National Library of Canada
Acquisitions and Bibliographic Services Branch
395 Wellington Street
Ottawa, Ontario
K1A 0N4

Bibliothèque nationale du Canada
Direction des acquisitions et des services bibliographiques
395, rue Wellington
Ottawa (Ontario)
K1A 0N4

Your file Votre référence

Our file Notre référence

NOTICE

The quality of this microform is heavily dependent upon the quality of the original thesis submitted for microfilming. Every effort has been made to ensure the highest quality of reproduction possible.

If pages are missing, contact the university which granted the degree.

Some pages may have indistinct print especially if the original pages were typed with a poor typewriter ribbon or if the university sent us an inferior photocopy.

Reproduction in full or in part of this microform is governed by the Canadian Copyright Act, R.S.C. 1970, c. C-30, and subsequent amendments.

AVIS

La qualité de cette microforme dépend grandement de la qualité de la thèse soumise au microfilmage. Nous avons tout fait pour assurer une qualité supérieure de reproduction.

S'il manque des pages, veuillez communiquer avec l'université qui a conféré le grade.

La qualité d'impression de certaines pages peut laisser à désirer, surtout si les pages originales ont été dactylographiées à l'aide d'un ruban usé ou si l'université nous a fait parvenir une photocopie de qualité inférieure.

La reproduction, même partielle, de cette microforme est soumise à la Loi canadienne sur le droit d'auteur, SRC 1970, c. C-30, et ses amendements subséquents.

Canada

UNIVERSITY OF ALBERTA

PEDIATRIC HEALTH-CARE PROFESSIONALS' PERCEPTIONS AND PRACTICES OF FAMILY-CENTRED CARE

BY

© NICOLE L. LETOURNEAU

A thesis submitted to the Faculty of Graduate Studies and Research in partial fulfillment of the requirements for the MASTER OF NURSING DEGREE

FACULTY OF NURSING

EDMONTON, ALBERTA

FALL, 1994

National Library of Canada
Acquisitions and Bibliographic Services Branch
395 Wellington Street
Ottawa, Ontario
K1A 0N4

Bibliothèque nationale du Canada
Direction des acquisitions et des services bibliographiques
395, rue Wellington
Ottawa (Ontario)
K1A 0N4

Your file Votre référence

Our file Notre référence

The author has granted an irrevocable non-exclusive licence allowing the National Library of Canada to reproduce, loan, distribute or sell copies of his/her thesis by any means and in any form or format, making this thesis available to interested persons.

L'auteur a accordé une licence irrévocable et non exclusive permettant à la Bibliothèque nationale du Canada de reproduire, prêter, distribuer ou vendre des copies de sa thèse de quelque manière et sous quelque forme que ce soit pour mettre des exemplaires de cette thèse à la disposition des personnes intéressées.

The author retains ownership of the copyright in his/her thesis. Neither the thesis nor substantial extracts from it may be printed or otherwise reproduced without his/her permission.

L'auteur conserve la propriété du droit d'auteur qui protège sa thèse. Ni la thèse ni des extraits substantiels de celle-ci ne doivent être imprimés ou autrement reproduits sans son autorisation.

ISBN 0-315-94979-1

Canada

Name Nicole Lefoumeau

Dissertation Abstracts International is arranged by broad, general subject categories. Please select the one subject which most nearly describes the content of your dissertation. Enter the corresponding four-digit code in the spaces provided.

SUBJECT TERM

SUBJECT CODE 0569

U·M·I

Subject Categories

THE HUMANITIES AND SOCIAL SCIENCES

COMMUNICATIONS AND THE ARTS
Architecture 0729
Art History 0377
Cinema 0900
Dance 0378
Fine Arts 0357
Information Science 0723
Journalism 0391
Library Science 0399
Mass Communications 0708
Music 0413
Speech Communication 0459
Theater 0465

EDUCATION
General 0515
Administration 0514
Adult and Continuing 0516
Agricultural 0517
Art 0273
Bilingual and Multicultural 0282
Business 0688
Community College 0275
Curriculum and Instruction 0727
Early Childhood 0518
Elementary 0524
Finance 0277
Guidance and Counseling 0519
Health 0680
Higher 0745
History of 0520
Home Economics 0278
Industrial 0521
Language and Literature 0279
Mathematics 0280
Music 0522
Philosophy of 0998
Physical 0523

Psychology 0525
Reading 0535
Religious 0527
Sciences 0714
Secondary 0533
Social Sciences 0534
Sociology of 0340
Special 0529
Teacher Training 0530
Technology 0710
Tests and Measurements 0288
Vocational 0747

LANGUAGE, LITERATURE AND LINGUISTICS
Language
- General 0679
- Ancient 0289
- Linguistics 0290
- Modern 0291

Literature
- General 0401
- Classical 0294
- Comparative 0295
- Medieval 0297
- Modern 0298
- African 0316
- American 0591
- Asian 0305
- Canadian (English) 0352
- Canadian (French) 0355
- English 0593
- Germanic 0311
- Latin American 0312
- Middle Eastern 0315
- Romance 0313
- Slavic and East European 0314

PHILOSOPHY, RELIGION AND THEOLOGY
Philosophy 0422
Religion
- General 0318
- Biblical Studies 0321
- Clergy 0319
- History of 0320
- Philosophy of 0322

Theology 0469

SOCIAL SCIENCES
American Studies 0323
Anthropology
- Archaeology 0324
- Cultural 0326
- Physical 0327

Business Administration
- General 0310
- Accounting 0272
- Banking 0770
- Management 0454
- Marketing 0338

Canadian Studies 0385
Economics
- General 0501
- Agricultural 0503
- Commerce-Business 0505
- Finance 0508
- History 0509
- Labor 0510
- Theory 0511

Folklore 0358
Geography 0366
Gerontology 0351
History
- General 0578
- Ancient 0579
- Medieval 0581
- Modern 0582
- Black 0328
- African 0331
- Asia, Australia and Oceania 0332
- Canadian 0334
- European 0335
- Latin American 0336
- Middle Eastern 0333
- United States 0337

History of Science 0585
Law 0398
Political Science
- General 0615
- International Law and Relations 0616
- Public Administration 0617

Recreation 0814
Social Work 0452
Sociology
- General 0626
- Criminology and Penology 0627
- Demography 0938
- Ethnic and Racial Studies 0631
- Individual and Family Studies 0628
- Industrial and Labor Relations 0629
- Public and Social Welfare 0630
- Social Structure and Development 0700
- Theory and Methods 0344

Transportation 0709
Urban and Regional Planning 0999
Women's Studies 0453

THE SCIENCES AND ENGINEERING

BIOLOGICAL SCIENCES
Agriculture
- General 0473
- Agronomy 0285
- Animal Culture and Nutrition 0475
- Animal Pathology 0476
- Food Science and Technology 0359
- Forestry and Wildlife 0478
- Plant Culture 0479
- Plant Pathology 0480
- Plant Physiology 0817
- Range Management 0777
- Wood Technology 0746

Biology
- General 0306
- Anatomy 0287
- Biostatistics 0308
- Botany 0309
- Cell 0379
- Ecology 0329
- Entomology 0353
- Genetics 0369
- Limnology 0793
- Microbiology 0410
- Molecular 0307
- Neuroscience 0317
- Oceanography 0416
- Physiology 0433
- Radiation 0821
- Veterinary Science 0778
- Zoology 0472

Biophysics
- General 0786
- Medical 0760

EARTH SCIENCES
Biogeochemistry 0425
Geochemistry 0996
Geodesy 0370
Geology 0372
Geophysics 0373
Hydrology 0388
Mineralogy 0411
Paleobotany 0345
Paleoecology 0426
Paleontology 0418
Paleozoology 0985
Palynology 0427
Physical Geography 0368
Physical Oceanography 0415

HEALTH AND ENVIRONMENTAL SCIENCES
Environmental Sciences 0768
Health Sciences
- General 0566
- Audiology 0300
- Chemotherapy 0992
- Dentistry 0567
- Education 0350
- Hospital Management 0769
- Human Development 0758
- Immunology 0982
- Medicine and Surgery 0564
- Mental Health 0347
- Nursing 0569
- Nutrition 0570
- Obstetrics and Gynecology 0380
- Occupational Health and Therapy 0354
- Ophthalmology 0381
- Pathology 0571
- Pharmacology 0419
- Pharmacy 0572
- Physical Therapy 0382
- Public Health 0573
- Radiology 0574
- Recreation 0575
- Speech Pathology 0460
- Toxicology 0383

Home Economics 0386

PHYSICAL SCIENCES
Pure Sciences
Chemistry
- General 0485
- Agricultural 0749
- Analytical 0486
- Biochemistry 0487
- Inorganic 0488
- Nuclear 0738
- Organic 0490
- Pharmaceutical 0491
- Physical 0494
- Polymer 0495
- Radiation 0754

Mathematics 0405
Physics
- General 0605
- Acoustics 0986
- Astronomy and Astrophysics 0606
- Atmospheric Science 0608
- Atomic 0748
- Electronics and Electricity 0607
- Elementary Particles and High Energy 0798
- Fluid and Plasma 0759
- Molecular 0609
- Nuclear 0610
- Optics 0752
- Radiation 0756
- Solid State 0611

Statistics 0463

Applied Sciences
Applied Mechanics 0346
Computer Science 0984
Engineering
- General 0537
- Aerospace 0538
- Agricultural 0539
- Automotive 0540
- Biomedical 0541
- Chemical 0542
- Civil 0543
- Electronics and Electrical 0544
- Heat and Thermodynamics 0348
- Hydraulic 0545
- Industrial 0546
- Marine 0547
- Materials Science 0794
- Mechanical 0548
- Metallurgy 0743
- Mining 0551
- Nuclear 0552
- Packaging 0549
- Petroleum 0765
- Sanitary and Municipal 0554
- System Science 0790

Geotechnology 0428
Operations Research 0796
Plastics Technology 0795
Textile Technology 0994

PSYCHOLOGY
General 0621
Behavioral 0384
Clinical 0622
Developmental 0620
Experimental 0623
Industrial 0624
Personality 0625
Physiological 0989
Psychobiology 0349
Psychometrics 0632
Social 0451

LETTER OF UNDERSTANDING BETWEEN INVESTIGATORS
FOR THE STUDY ENTITLED:

PAEDIATRIC HEALTH CARE PROFESSIONALS' PERCEPTIONS AND PRACTICES OF FAMILY-CENTRED CARE

This signed document represents our agreement that all raw data collected at each of three sites of this multi-site study belongs to the respective investigator at each site. As such, Beth Bruce owns her raw data, Christine Dennis owns her raw data, and Nicole Letourneau owns her raw data.

Each investigator may publish site-specific results of the study independently of the other two investigators. However, if this occurs, it must be noted in any publication that the site-specific results are part of a larger, multi-site study. Independent publication of any one investigator should acknowledge the other investigators of the larger study (i.e., this refers to an *acknowledgement* only, and not a requirement to share authorship on any independent publication). The investigators are committed to pooling the site-specific raw data in order to meet the objectives of the larger study; namely, to compare family-centred care perceptions and practices of health care professionals across 3 paediatric sites. Publication of the pooled results will occur as soon as possible after completion of the study, and in this circumstance authorship will be shared among the investigators.

This signed document also grants permission from Beth Bruce for Christine Dennis and Nicole Letourneau to use the copyrighted Family-Centred Care Questionnaire - Revised (FCCQ-R, 1993) for the purposes of this study. Beth Bruce will be acknowledged in any reference made to the FCCQ-R.

Beth Bruce — Nov 26/93

Beth Bruce — Date

Christine Dennis — Nov. 26th/93

Christine Dennis — Date

N Letourneau — November 28, 1993

Nicole Letourneau — Date

UNIVERSITY OF ALBERTA

RELEASE FORM

NAME OF AUTHOR: Nicole L. Letourneau

TITLE OF THESIS: Pediatric Health-Care Professionals' Perceptions and Practices of Family-Centred Care.

DEGREE: Master of Nursing

YEAR THIS DEGREE GRANTED: Fall, 1994

Permission is hereby granted to the University of Alberta Library to reproduce single copies for private, scholarly or scientific purposes only.

The author reserves all other publication and other rights in association with the copyright in the thesis, and except as hereinbefore provided neither the thesis nor any substantial portion thereof may be printed or otherwise reproduced in any material form whatever without the author's prior written permission.

Faculty of Nursing
3rd Floor, Clinical Sciences Building
University of Alberta
Edmonton, Alberta

August 30, 1994

UNIVERSITY OF ALBERTA

FACULTY OF GRADUATE STUDIES AND RESEARCH

The undersigned certify that they have read, and recommend to the Faculty of Graduate Studies and Research for acceptance, a thesis entitled PEDIATRIC HEALTH-CARE PROFESSIONALS' PERCEPTIONS AND PRACTICES OF FAMILY-CENTRED CARE submitted by Nicole L. Letourneau in partial fulfillment of the requirements for the degree of Master of Nursing.

M. Ruth Elliott
Dr. M. Ruth Elliott (Supervisor)

Jane Drummond
Dr. Jane Drummond

Herbert Northcott
Dr. Herbert Northcott

Janice Lander
Dr. Janice Lander (Chair)

August 18, 1994

DEDICATION

To Dean,

"If two were ever one, then surely we.

If ever man were loved by a wife then thee..."

To My Family,

My Mother: "You'd better start saving for university!"

My Father: "You should stay in Nursing."

ABSTRACT

The purpose of this study is to describe health-care professionals' ratings of their perceptions and practices of the components of family-centred care at the Alberta Children's Hospital in Calgary. An improved understanding of the ability of health-care professionals to practice family-centred care is essential to an accurate determination of the possible barriers to practice such as perceptual influences, organizational factors, and demographic variables. Subjects were asked to complete the Family-Centred Care Questionnaire-Revised (FCCQ-R) (Bruce, 1993) which measures perceptions and practices of family-centred care and presents open-ended questions about family-centred care. One hundred and seventy-one completed responses were obtained for a response rate of 36%. It was suggested by the findings that there is a significant difference between perceptions and practice of family-centred care ($p<.001$). Analysis of the demographic variables revealed that social workers and older subjects contributed positively to the scores obtained on the practice scale of the family-centred care questionnaire. Bachelor's prepared health-care professionals contributed positively to perception scores. In contrast, physicians and subjects with postsecondary education or a professional specialty as their highest level of education contributed negatively to the scores obtained on the perceptions scale of family-centred care. Staff members as opposed to educational or administrative staff also contributed negatively to perception scores. The findings suggest that the "dilemma of helping", education and knowledge, experience, financial and time constraints, staff position, communication and the organizational setting influence health-care professionals' abilities to practice family-centred care.

ACKNOWLEDGEMENTS

I wish to extend my heartfelt thanks to all those who have contributed to this thesis. I would especially like to thank my supervisor and mentor, Dr. M. Ruth Elliott, who has provided me with inspiration, insight and countless hours of support and encouragement. I would also like to thank my other committee members, Dr. Jane Drummond and Dr. Herbert Northcott for their time, advice and support.

I must also thank Beth Bruce, Dr. Judith Ritchie and Christine Dennis for their work and negotiation with a 'difficult' graduate student. The Alberta Children's Hospital, especially Laurie Wilson, Mary Perry, Mary 'the secretary', Nora Greenley, Dr. Gerald Goresky and Diane Ellingson deserve thanks.

Terry Taerum, Dr. Janice Lander, Dr. Louise Jensen and Cliff Kinsel provided invaluable statistical knowledge and advice.

Brent and Jana Wilson provided me with 'Maritime Hospitality' whenever I needed a place to stay in Calgary.

I also want to acknowledge the National Health Research and Development Program and the Canadian Nurses Foundation for providing financial support for this research.

TABLE OF CONTENTS

CHAPTER PAGE

I. INTRODUCTION....1

Background....1

Historical Origins....1

Family-centred care....2

Benefits....4

Barriers....5

The Need for Research....6

Purpose....6

Research Question....7

Definition of Terms....7

Health-Care Professional....7

Perception....7

Practice....7

Family-Centred Care....7

Objectives....8

Conceptual Framework....8

II. REVIEW OF THE LITERATURE....9

Family-Centred Care....9

Benefits of Family-Centred Care....9

Effects on Children....9

Reduced Maternal Deprivation....9

Reduced Separation Anxiety....10

Improved Health....10

Psychosocial Outcomes....10

Physical Outcomes....12

CHAPTER PAGE

Effects on Families.....12

Enhanced Learning.....12

Reduced Stress.....14

Better Quality Care.....15

Organizational Effects.....16

Reduced Costs.....16

Job Enhancement.....17

Barriers to Family-Centred Care.....17

Perceptions.....18

Education and Knowledge.....20

Level of Education.....20

Educational Content.....21

Professional Discipline.....22

Staff Position and Experience.....24

Organizational Setting.....24

Time and Personnel Availability.....25

Role Negotiation and Communication.....26

Costs.....27

Parental and Marital Status.....27

Summary.....28

III. METHOD.....30

Research Design.....30

The Sample.....30

External and Internal Validity.....31

Data Collection.....31

Instrument.....33

CHAPTER PAGE

Validity and Reliability....34
Pilot Test....34
Data Analysis....35
Ethical Considerations....36
IV. FINDINGS....37
Introduction....37
Description of the Sample....37
Final Sample Description of Losses....37
Sample Characteristics and Descriptive Data....38
Major Findings....44
Total Scale, Subscale and Item Scores....45
Relationships Between Demographic Variables and Scores on the Perceptions and Practice Scales....47
Secondary Findings....50
Factor Analysis....51
Content Analysis....52
Question 1 "Do you think there is a large difference between your everyday work and what you think is necessary to practice family-centred care? If so, why? If not, why?"....53
"Yes, there is a large difference."...53

CHAPTER PAGE

"No, there is not a large difference."....53
Indecisive....54
Question 2: "If there are instances in which you become child-centred instead of family-centred in your approach to care, please describe."....54
Child's Well-Being At Stake....54
Dysfunctional or Absent Families....54
Older Children....54
Professional Judgement....55
Child's Needs Considered First....55
Queston 3: "Please list any suggestions of what is needed to enhance family-centred care."....55
Financial Resources....55
Time....56
Education....56
Family Participation....56
Communication....57
Question 4: "Please write any additional comments below."....57
Summary....57
V. DISCUSSION....58
Summary of Findings....58
Discussion of Findings....60

CHAPTER PAGE

Perceptions....60
Education and Knowledge....61
Experience....62
Staff Position....62
Communication....63
Financial and Time Constraints....63
Parental Status....63
Organizational Setting....63
Limitations....64
Family-Centred Care Questionnaire-Revised..64
Generalizability....65
Implications of Findings....66
The Effect of the Cohort....66
The Dilemma of Helping....67
Practice....68
Education....69
Research....70
Conclusions....71
REFERENCES....72
APPENDIX
A Family-Centred Care Model....84
B Family-Centred Care Questionnaire-Revised....85
C Statement of Alberta Children's Hospital Family-Centred Care Philosophy....96
D Interim Approval Letter....97
E Final Approval Letter....98

APPENDIX PAGE

F Announcement for Newsletter.....99

G Flyer.....100

H Information Bulletin.....101

I First Cover Letter.....102

J Postcard.....103

K Second Cover Letter.....104

L Third Cover Letter.....105

M Original Family-Centred Care Questionnaire-Revised.....106

N Original File: Factor Loadings and Eigenvalues for Perceptions Scale.....112

O Original File: Factor Loadings and Eigenvalues for Practice Scale.....114

P Final File: Factor Loadings and Eigenvalues for Perceptions Scale.....116

Q Final File: Factor Loadings and Eigenvalues for Practice Scale.....118

R Figures.....120

S FCCQ-R Item Mean Scores From Lowest to Highest.....137

LIST OF TABLES

TABLE PAGE

4.1 Health-Care Professionals' Perceptions of Family-Centred Care: Mean Total Scores.....39

4.2 Health-Care Professionals' Practice of Family-Centred Care: Mean Total Scores.....40

4.3 Perception Scores According to Area of Employment.....41

4.4 Practice Scores According to Area of Employment.....41

4.5 Perception Scores According to Age Group.....42

4.6 Practice Scores According to Age Group.....42

4.7 Perception Scores According to Years of Experience.....42

4.8 Practice Scores According to Years of Experience.....43

4.9 Perception Scores According to Highest Level of Education Obtained.....43

4.10 Practice Scores According to Highest Level of Education Obtained.....44

4.11 Perception Scores According to Parental Status.....44

4.12 Practice Scores According to Parental Status.....44

4.13 Perception and Practice Scale Scores.....46

4.14 One-Way Analysis of Variance of Perception Scores by Highest Level of Education Obtained.....48

4.15 T-Test for Differences Between Older and Younger Subjects on Practice Scores.....48

4.16 The Contribution of Significant Variables to Perception Scores in the Regression Equation.....49

TABLE PAGE

4.17 The Contribution of Significant Variables to Practice Scores in the Regression Equation.....49

4.18 Perception Scale Internal Reliability Coefficients...52

4.19 Practice Scale Internal Reliability Coefficients.....52

LIST OF FIGURES

FIGURE		PAGE
1	Sample Percentages by Health-Care Profession	121
2	Mean Perception Scores by Health-Care Profession	122
3	Mean Practice Scores by Health-Care Profession	123
4A	Sample Subgroup Counts by Area of Employment	124
4B	Sample Percentages for Recoded Area of Employment	125
5	Mean Perception Scores by Recode of Area of Employment	126
6	Mean Practice Scores by Recode of Area of Employment	127
7	Sample Percentages by Age Group	128
8	Mean Perception Scores by Age Group	129
9	Mean Practice Scores by Age Group	130
10	Sample Percentages by Years of Experience	131
11	Mean Perception Scores by Years of Experience	132
12	Mean Practice Scores by Years of Experience	133
13	Sample Percentages by Highest Level of Education	134
14	Mean Perception Scores by Highest Level of Education	135
15	Mean Practice Scores by Highest Level of Education	136

CHAPTER 1

INTRODUCTION

The Association for the Care of Children's Health in Bethesda, Maryland recently published a revolutionary document which defined the key elements of family-centred care (Shelton, Jeppson & Johnson, 1989). This document was prepared in response to the growing recognition by professionals that children's health care must be family-centred. Indeed, family-centred care has become a common goal among health-care professionals who work with children (Robinson, 1987). Family-centred care is a health care delivery model that seeks to fully involve families in the care of children through an approach that is respectful and supportive. When cared for in a system that promotes the practice of family-centred care, children experience less separation anxiety and maternal deprivation while parents' learning is enhanced (Palmer, 1993). However, some have questioned the viability of family-centred care in the workplace (Rushton, 1990; Odle, 1988).

Background

Beginning in the mid 1960's, pediatric health care leaders began to establish systems that recognized the emotional and developmental needs of children (Johnson, Jeppson, & Redburn, 1992). Previously, parents were forced to relinquish care for their children at the hospital doors (Brewis, 1986). Today, there is an understanding that the "unique and changing needs of the child demand that health care be organized and delivered in ways that support the whole child and the family" (Johnson, et al., 1992, p. 1). This represents a move from institution-centred care to family-centred care (Johnson, et al., 1992).

Historical Origins

The first hospitals for sick children were opened during the nineteenth century, but the majority of sick children continued to be cared for at home (Nethercott, 1993). Visiting in hospitals was restricted and the presence of families was felt to inhibit effective care (NAWCH, 1988). The change in perception of the importance of the family began with the Bowlby's (1951) work on the effects of maternal deprivation on infants and children. The Platt Report (1959) from England later recommended that parents should have unrestricted access to their children and that young children should be admitted with a parent. In 1987, the Surgeon General's Report from the United States outlined the elements of family-centred care with corresponding steps for action (Koop, 1987). Examples of

these elements included recognition that the family is the constant, sharing of unbiased and complete information with parents, and encouragement of normal patterns of living in the home and community.

Family-Centred Care

Perhaps as a result of the slow progression from institution-centred care to family-centred care, the concept of family-centred care in the pediatric setting has been historically difficult to define. Rushton (1990) indicated that "parents and professionals have been struggling to reach consensus" regarding the definition and implementation of the concept in practice (p. 68). Luciano (1972a) described the philosophy of family-centred care as giving recognition to the worth of the individual child as a member of the family. She further suggested that family-centred care include significant family members in establishing objectives to meet health care needs of the child. It implies a systematic approach to the identification and resolution of family needs in an environment conducive to therapeutic relationships. She described family-centred care as an "open system extending across all hospital services, each service having a particular effect on a hospitalization experience" (Luciano, 1972b, p. 75). Fond (1972) indicated that the goal of family-centred care was to maintain or strengthen the roles and ties of the family with the hospitalized child in order to promote normalcy of the family unit.

In the community health setting, Yauger (1972) was the first to define family-centred care as "the identification of problems and needs of a family and the provision of appropriate service for every member" (p. 320). Porter (1979) ventured a more complete description by defining family-centred care explicitly "as an open, multidimensional system of health management which acknowledges the inseparability of the individual from his [and her] family and environment and which effectively and efficiently utilizes the complementary skills of all members of the health team, including the client and his family" (p. 330). She also suggested that family-centred care activities depend upon a team which enjoys open communication and coordination of goal-directed efforts. Further, family-centred care requires creativity and flexibility, yet demands a systematic process to meet the dynamic needs of clients (Porter, 1979).

Rushton (1990) suggested that "a giant step toward...consensus regarding the definition of the term as well as the design of a family-centred approach to care...has been made by opening the lines of communication

between parents and professionals" in the guise of the Association for the Care of Children's Health (ACCH) (p. 68). As such, family-centred care was more clearly defined by the ACCH as:

> a philosophy of care that recognizes and respects the pivotal role of the family in the lives of children with special health needs. It is a philosophy that strives to support families in their natural caregiving roles by building upon their unique strengths as individuals and as families. It is a philosophy that views parents and professionals as equals in a partnership committed to excellence at all levels of health care. (Shelton, Jeppson & Johnson, 1987, p. 2)

Shelton, Jeppson and Johnson (1987 & 1989) describe eight equally important components of family-centred care. These include:

1. Recognition that the family is the constant in the child's life while the service system and personnel within those systems fluctuate.
2. Facilitation of parent/professional collaboration at all levels of health care.
3. Recognition of family strengths and individuality, and respect for different methods of coping.
4. Sharing of unbiased and complete information with parents about their child's care on an ongoing basis in an appropriate and supportive manner.
5. Encouragement and facilitation of parent-to-parent support.
6. Understanding and incorporating the developmental needs of infants, children, and adolescents and their families into health care delivery systems.
7. Implementation of appropriate policies and programs that are comprehensive and provide emotional and financial support to meet the needs of families.
8. Assurance that the design of health care delivery systems is flexible, accessible and responsive to family needs.

The Izaak Walton Killam Children's Hospital Family-Centred Care Committee (1992) as cited in Bruce (1992) subsequently modified these to include a ninth element of:

9. Implementation of appropriate policies and programs that are comprehensive and provide emotional support to meet the needs of staff. (Appendix A).

Formerly considered under element three, which stresses family individuality, the ACCH also recently expanded the concept of family-centred care to include "honouring the

racial, ethnic, cultural, and socioeconomic diversity of families" (Johnson et al., 1992, p. 3). Shelton et al. (1989) suggest that these broad elements propose a revolutionary shift in the treatment of children with disabilities in that the family, as the primary decision maker, becomes central to service delivery. Shelton et al. (1989) indicate that professionals and families must work together to balance medical recommendations with the priorities of families so that programs truly meet family needs and goals. In a family-centred approach to care, programs must be designed with the individuality of families in mind and with the flexibility to tailor services to the unique strengths of each child and family (Shelton et al., 1989).

Dunst, Trivette, Davis and Cornwell (1988a) suggested that the elements of family-centred care are based upon principles which are designed to promote self-determination, decision-making, capabilities, control and self-efficacy. Collectively, these attributes are said to reflect a sense of empowerment and an enablement model of helping. More recent literature has indicated that increased participation at all levels of health care has become a major goal of family-centred service systems (Hutchins & McPherson, 1991). Further, Dunst, Johanson, Trivette and Hamby (1991) referred to family-centred care as a combination of beliefs and practices that define particular ways of working with families that are consumer driven and competency enhancing. Nethercott (1993) examined the concept of family-centred independent of the work of the ACCH. She agreed that "family-centred care has several critical components" and outlined the skills necessary to practice family-centred care (p. 796). Nethercott suggests that a combination of education, practice and life skills enables nurses to practice family-centred care. McBride, Brotherson, Joanning, Whiddon and Demmitt (1993) outlined three major principles of family-centred care "that most encompass current values and practice" (p. 415). These include establishing the family as the focus of services, supporting and respecting family decision-making, and providing intervention services designed to strengthen family functioning.

Benefits

The benefits arising from parental participation in children's care in hospital are well recognized in the expository literature (George & Hancock, 1993; Green & Green, 1977; Harris, 1990; MacCarthy, 1957; Marriott, 1990; McElnea, 1971; Mason, 1978; Pass & Pass, 1987; Patterson, 1979; Spence, 1947 & 1951). Others have explicitly referred to the benefits of family-centred care (Arrango, 1990;

Bailey, McWilliam & Winton, 1992; Kelly, 1993; McKenzie, Kurtianyk, Kidd, Knowles & Lipman, 1993; Nissen, 1969; Odle, 1988; Robbins, 1987; Roberts & Magrab, 1991). Still others have described the implementation of a family-centred care model into the institutional setting (Burrows, 1972; Goodley, 1985; Korteland & Cornwell, 1991; Pike, 1989; Robbins, 1991; Shea-McAlveavey & Janusz, 1991; Siegel, 1982; Thompson, 1985).

Palmer (1993) indicates that parents' competence and confidence in dealing with childrens' illness increases when included as part of the health care team, because they feel useful and important. Increased interaction between parents and staff results in a lessening of communication gaps (Van der Schyff, 1979) and a greater likelihood of parents to share confidences and anxieties with staff (Palmer, 1993). Robbins (1991) indicates that family-centred care minimises the trauma of a hospital stay and allows an independence and quality of life that would otherwise be impossible to achieve.

Although family-centred care has received substantial recognition as a satisfying and useful experience for children and their families, it "has not found its rightful place in health centres or among health care workers" (Porter, 1979, p. 330). Many health-care professionals respect and support the idea of family-centred care, but few actually put it into practice (Blumenstein, 1986; Porter, 1979).

Barriers

The barriers to family-centred care are also well recognized in the expository literature (Ayer, 1978; Blumenstein, 1986; Dunst, Trivette, Davis & Cornwell, 1988a; Gill, 1987b; Meadow, 1969; Robinson, 1985). Rushton (1990) cited professional attitudes, understaffing, insufficient resources, and lack of administrative support as influencing the ability to provide family-centred care. Other factors included lack of training, adherence to child-focused practices, and a lack of clearly articulated set of procedures for family-centred care (Bailey, McWilliam & Winton, 1992). Further, Leavitt (1984) indicated that many professionals want to apply this knowledge, but are unable because of time or organizational constraints, lack of experience or practical preparation, and "a tenuous sense of legitimacy" about family participation (p. 84).

Health-care professionals often question parents' ability to participate in decision making, particularly when parental decisions are not congruent with their own (Rushton, 1990). Some professionals perceive that parental

involvement will place increased demands on them while they do not have the extra time needed to monitor parent performance (Eldar & Eldar, 1984). Professionals may mistrust parents' competence to contribute to the care of the critically ill child (Dunkel & Eisendrath, 1983). Thomas (1987) suggested that professionals may also fear loss of control over patient outcomes in the already unpredictable critical care environment if parent involvement is increased. Whatever the cause, when the health-care professional "assumes the role of expert caregiver at the expense of the parent, tensions build" and an unhealthy relationship is established between families and staff (Rushton, 1990, p. 70).

The Need for Research

In 1979, Porter suggested that the relationship between health-care professionals' orientation to family-centred care and clinical practice be studied to determine whether or not attitudinal factors underlie behaviour. In 1990, Rushton echoed this sentiment indicating a need to examine the attitudes of health-care professionals and administrators about the role of families in health settings. Roberts and Magrab (1991) contend that as institutions become more involved in family-centred care, research is needed to inform practice and training.

Results from this research are expected to provide insight into health-care professionals' perceptions of the barriers to practising family-centred care. They will also show to what degree family-centred care is practised and emphasize the importance health-care professionals attach to being able to practice family-centred care. This will help to clarify assumptions and questions about the viability of family-centred care for children, families and health-care professionals.

Purpose

The purpose of this study is to explore and describe health-care professionals' ratings of their perceptions and practices of the components of family-centred care at the Alberta Children's Hospital in Calgary in 1994. An improved understanding of the ability of health-care professionals to practice family-centred care is essential to determine with some degree of accuracy the possible barriers to practice such as perceptual influences, organizational factors, and demographic variables. This will provide a basis for the development of policies and programs to enable health-care professionals to practice family-centred care more effectively.

Research Question

What are pediatric health-care professionals' perceptions and reported practices of family-centred care?

Definition of Terms

Health-Care Professionals

Health-care professionals include staff employed as child life specialists, nurses, nutritionists, occupational therapists, pharmacists, physicians, physiotherapists, psychologists, respiratory therapists, social workers, and speech/language pathologists/audiologists.

Perception

The health-care professional's rating of the necessity of a given element of family-centred care as measured on the Family-Centred Care Questionnaire-R (FCCQ-R).

Practice

The health-care professional's rating of the extent to which a given element of family-centred care is currently included in everyday work as measured on the FCCQ-R.

Family-Centred Care

Shelton, Jeppson and Johnson (1987 & 1989) describe eight equally important components of family-centred care. These include:

1. Recognition that the family is the constant in the child's life while the service system and personnel within those systems fluctuate.
2. Facilitation of parent/professional collaboration at all levels of health care.
3. Recognition of family strengths and individuality, and respect for different methods of coping.
4. Sharing of unbiased and complete information with parents about their child's care on an ongoing basis in an appropriate and supportive manner.
5. Encouragement and facilitation of parent-to-parent support.
6. Understanding and incorporating the developmental needs of infants, children, and adolescents and their families into health care delivery systems.
7. Implementation of appropriate policies and programs that are comprehensive and provide emotional and financial support to meet the needs of families.
8. Assurance that the design of health care delivery

systems is flexible, accessible and responsive to family needs.

The Izaak Walton Killam Children's Hospital Family-Centred Care Committee (1992) as cited in Bruce (1992) subsequently modified these to include a ninth element of:

9. Implementation of appropriate policies and programs that are comprehensive and provide emotional support to meet the needs of staff. (Appendix A)

Objectives

1. To describe health-care professionals' perceptions of the extent to which the nine key elements of family-centred care are necessary to practice family-centred care.
2. To describe health-care professionals' reports of the extent to which the nine key elements of family-centred care are present in their practice.
3. To determine if a discrepancy exists between health-care professionals' ratings of the necessity of family-centred care and their rating of their practice of family-centred care.
4. To determine if the dependent variables of perceptions and practices of health-care professionals vary as an effect of the independent variables of professional group, age group, position, education, experience, and parental status (Bruce, 1993).

Conceptual Framework

This study and research instrument have been developed within the framework of family-centred care as proposed by the ACCH (Shelton et al., 1987 & 1989) and modified by the Family-Centred Care Committee at the Izaak Walton Killam Hospital for Children (1992) in Halifax, Nova Scotia (Appendix A).

CHAPTER II

REVIEW OF THE LITERATURE

Family-Centred Care

The concept of family-centred care and related topics such as parental participation and family involvement have been explored by an extensive review of the published research from nursing, medicine, psychology, education, and other related fields. Computer data bases including CINAHL, ERIC, HealthPLAN, MEDLINE, PsycLIT, and sociofile were searched. The review of the literature shows that there are many benefits and barriers to incorporating the family into children's health care.

Benefits of Family-Centred Care

The benefits of including families in the care of their hospitalized children are well demonstrated in the research. These benefits have been explored from a variety of perspectives and include effects on children, families and organizations.

Effects on Children

The effects of incorporating the family into the care of hospitalized children were studied long before the development of the more modern definitions of family-centred care. As a result, none of these early studies defined family-centred care or used the ACCH family-centred care model. More importantly, these studies created the convincing basis for the modern day acceptance of the importance of family-centred care for children. Indeed, many of the elements of family-centred care were derived from these early studies.

Reduced Maternal Deprivation

Spitz (1945) studied 164 children in long-term care institutions and compared them with children reared in families. Upon observing severe developmental retardation in the institutionalized children, the researcher stressed the "unique importance of [an] adequate and satisfactory mother-child relationship" (p. 72). Bowlby and Robertson investigated the effects of the separation of children from their mothers in early childhood on subsequent personality development (Robertson & Bowlby, 1952; Bowlby, 1953; Bowlby, 1960; Robertson, 1953). Based on four years of observations of forty-nine 1- to 4-year-olds undergoing separation experiences, the researchers concluded that the separation of young children from their mothers produces "much mental

ill-health" (Bowlby, 1953, p. 272). Bowlby (1953) outlined the essential nature of the maternal-infant bond and the need for an attachment-figure during hospitalization. He later warned that 'maternal deprivation' could result from parent-child separation or the denial of a warm, intimate and continuous relationship with the mother or nurturing person (Bowlby, 1957).

Reduced Separation Anxiety

Prugh, Staub, Sands, Kirschbaum, & Lenihan (1953) explored the psychologic effects of hospitalization on 100 children aged two to 12 years when separated and accompanied by parents. Findings suggest that children three years of age and younger are most susceptible to separation from the mother, although "separation anxiety" may also occur in older children (Prugh, et al., 1953, p. 101). Schaffer and Callender (1959) studied the effect of separation from parents on 76 hospitalized infants aged three to 51 weeks. The infants also illustrated separation anxiety consisting of "protest during the initial period of hospitalization, negativism to the staff,...withdrawal, and a period of readjustment after return home, during which a great deal of insecurity centering on the mother's presence was shown" (Schaffer & Callendar, 1959, p. 537).

Frankl, Shiere, and Fogels (1962) studied the effects of separation of the mother and pre-school child on 112 children in the dental office. The experimental and control conditions consisted of observations of children kept with and separated from their mothers respectively during treatment. It is indicated by the results that 96% of the children kept with their mothers responded positively to the treatment experience. In contrast, only 48% of children separated from their mothers during treatment responded positively. A study by Schulman, Foley, Vernon, and Allan (1967) of thirty-two 2- to 6-year old children admitted for tonsillectomy confirmed these results suggesting that "children accompanied during induction [of anaesthesia] were less upset than those who were separated" (p. 112). These results confirm other research findings on the negative psychological implications of parent-child separation during hospitalization (Illingworth & Holt, 1955; Jessner, Blom & Waldfogel, 1952; Kay, 1966; Plank, Caughey & Lipson, 1959; Vaughn, 1957).

Improved Health

Psychosocial outcomes.

Brain and Maclay (1968) studied 197 children under six years of age admitted to hospital with their mothers or

alone. They found "a significant reduction in the incidence of emotional and infective complications" in the experimental group admitted with their mothers (p. 279). Child behavioural disturbances such as disturbed nights, clinging behaviour, aggression, and crying were observed in 22% of the experimental group and 55% of the control.

Gillette, Hansen, Robinson, Kirkpatrick and Grywalski (1990) performed a study of outcomes of infants with suspected developmental delay. Infants were obtained through admission to a neonatal intensive care unit at an American children's hospital. The infants had moderate to severe bronchopulmonary dysplasia or neurologic dysfunction. Infants and families were randomly assigned to one of two treatment interventions. One intervention was called the 'transition team case management model' which provided education to families regarding the benefits of early intervention in health, multidisciplinary development and family support (n=12). This treatment may be considered to contain elements of family-centred care. The control intervention was assignment to the 'traditional discharge' and community follow-up routine (n=12). Data on the infants at discharge indicate that they were comparable on the developmental scores on the Batelle Developmental Inventory. A comparison of mean scores at six months of age on the Bayley Mental Developmental Index favours the transition team infants. Transition team infants mean score was 98.4, while traditional discharge infants mean score was 79.0, approaching significance (t=1.95, p=.06). The Bayley Psychomotor Developmental Index for transition team infants was also higher, but not significantly. The lack of statistical significance and small sample size suggests limitations of the applicability of these research findings.

Ramey, Bryant, Wasik, Sparling, Fendt and LaVange (1992) performed a study of the effect of early intervention on the cognitive, behavioural and health status of low birth weight premature infants. The 377 intervention families received pediatric follow-up, home visits, parent support groups, and a systematic educational program for the first three years of life. Again, the strong focus on educating and incorporating the family suggests elements of family-centred care. The control group of 608 families received the same pediatric follow-up and referral services only. It was suggested by the findings that the intervention group performed better cognitively than did the pediatric follow-up group and the degree of participation was positively related to cognitive development. The 36-month Stanford-Binet Intelligence Quotient mean score for the intervention group was 93.5, compared with 84.5 with the control group. Intelligent Quotients are considered to be in the borderline intellectual functioning category if between 71 and 85.

Scores greater than 85 are considered in the normal range. It is not known whether this finding is significant as the results might be related to other program factors such as amount of parental participation rather than to family-centred care.

Physical outcomes.

In their study described above, Brain and Maclay (1968) also found that the incidence of cross-infection and post-operative complications was 11% in the experimental group compared with 23% in the control group. This confirmed previous observations that cross-infection among infants could be reduced by allowing mothers to care for their children while in hospital (Pickerill & Pickerill, 1954).

In a more recent study, Menzies, Parkin and Hey (1985) studied the effect of family-centred care on the health outcomes of 27 infants not offered immediate surgery for paralytic lumbar meningomyelocele at birth. Normally, these infants are not expected to survive very long. In this study, family-centred care simply represented caring for their infants at home. Remarkably, infants not offered surgery and cared for in a traditional hospital setting had a mortality rate of 100% by one month of life (n=209), whereas infants not offered surgery and cared for in a family-centred environment had a mortality rate of 30% at one month (n=27). Twenty-seven percent have since survived to school age. "All are chairbound and incontinent, but none is intellectually retarded and many are no more handicapped than children offered immediate surgical treatment at birth" (p. 993). The authors suggest that the high survival rate among the infants cared for at home may be due to an early change of expectation amongst those caring for the infant.

Effects on Families

As a result of the early literature on the negative consequences associated with child-parent separation during hospitalization, researchers began to examine the possibilities presented by alternative forms of pediatric health care that more adequately incorporated the family.

Enhanced Learning

Craig and McKay (1958) were among the first to study the advantages of including parents, especially mothers in pediatric health care. They surveyed 560 admissions to a mother and baby unit and found that mothers learned much more readily about their children's health when included. Further, "doctors and nurses...learn to better appreciate

the outlook of the mothers and to understand their worries and problems" (p. 277). In spite of the anecdotal reporting of the findings, this study is included for its early attention to the topic. The importance of this study is also limited by its greater emphasis on unit demographics than benefits to mothers.

Subsequently, Yauger (1972) studied the effect of family-centred care on health knowledge of families in the public health setting. Yauger (1972) provides an early definition of family-centred care, although it is not known whether the study is limited to families with children. The researcher found no significant differences were found between the experimental and control families, although health knowledge scores were greater in the experimental families.

Verghese (1988) performed a study of attitudes of 94 family members of mentally ill hospitalized patients. Families were encouraged to stay in hospital with the patient where they obtained more information about the illness and participated in the care. Measures of attitudes toward illness before and after the stay indicated a marked degree of change in knowledge and attitudes on various aspects of mental health and illness. Improvements were noted in perception of mental illness ($p<.001$), knowledge of etiology, treatment ($p<.01$) and rehabilitation ($p<.05$). Unfortunately, the population is not particular to children and families, suggesting limitations.

More recently, Lewis, Salas, de la Sota, Chiofalo and Leake (1990) assigned epileptic children and their families to either a child-centred, family-focused experimental condition ($n=123$) or a control group ($n=113$). Children in the experimental group and their parents separately attended four one and a half hour sessions and then met together at the end of each session to share learning experiences. Control children and their parents attended three two hour sessions with a traditional lecture format followed by question and answers. The experimental condition may be considered to contain more elements of family-centred care. Experimental and control groups were provided with equal educational content about epilepsy and seizure management. The experimental group children which learned in a family-centred care environment had greater increases in knowledge in all areas ($p<.001$-$.05$).

Caro and Derevensky (1991) implemented a family-focused home-based intervention model with 16 families having infants with moderate or severe disabilities. The intervention may be considered to contain many elements of family-centred care. Qualitative analyses of familial

behaviours suggested skill enhancement. Evaluation of the intervention resulted in high levels of parental satisfaction, accelerated rates of progress by children with disabilities, and acquisition of functional skills by families. Because these findings may be related to other factors such as the home visiting component of the intervention, the success cannot be attributed solely to family-centred care.

Reduced Stress

Mahaffy (1965) studied the effect of incorporating parents (mothers) into their children's hospitalization for tonsillectomy and adenoidectomy. An experimental group of 21 parent-child units were provided with an experimental nurse who attempted to determine mothers' needs, provide help and information, answer questions, or discuss "anything which caused the mother to be confused or unhappy" (p, 14). The control group of 23 parent-child units were cared for by the hospital personnel. The experimental nursing effort to help mothers cope included elements of family-centred care. Results showed that the experimental group of two to 10-year-old children "had lower temperatures, pulse rates, and systolic blood pressures than the control group. Also they voided within a shorter period of time, took larger quantities of fluid more easily, and had a lower incidence of vomiting" (p. 17). Further, the experimental group of children recovered in four days to one week in contrast to recovery periods longer than one week for controls ($p<.005$). The experimental group also presented fewer behavioural problems such as crying and disturbed sleep than did controls ($p<.05$).

Skipper and Leonard's (1968) follow-up study of eighty 3- to 9-year-old children admitted to hospital for tonsillectomy and adenoidectomy confirm these results. Findings suggested that the experimental condition of increased nurse-family interaction significantly reduced mothers' stress levels assessed by a questionnaire administered to mothers following discharge. The researchers believed that increasing the nurse-family interaction enabled mothers to redefine hospitalization as a more positive experience, thus reducing the child's stress and resulting in changes in social, psychological, and physiological behaviours. Another follow-up study by Wolfer and Visintainer (1975) also confirmed these results in their study of 80 children and their parents between the ages of three and fourteen. In addition to the above noted changes in children, experimental group parents who received special preparation and supportive care had "significantly lower self-ratings of anxiety, rated information received significantly higher in adequacy, and were significantly

more satisfied with their care" (p. 253).

Schulman, Foley, Vernon and Allan (1967) studied the effect of the mother's presence during anesthesia induction on 32 children between two and six years of age admitted for tonsillectomies. Half of the children were randomly assigned to the treatment condition of mother accompaniment, and half to the control condition of mother separation. Two of the three covariance analyses of mood provided support for the hypothesis that children accompanied during induction were less upset than those who were separated. This difference approached statistical significance during the period prior to induction and was statistically significant during induction.

Lewis, Hatton, Salas, Leake and Chiofalo (1991) performed a follow-up study on the parents of epileptic children who were exposed to a child-centred, family-focused intervention discussed above under enhanced learning. Parents in the experimental (n=185) and control groups (n=180) were evaluated at five months post-intervention and it was indicated by the findings that experimental group parents and especially mothers were more likely than controls to report that they were less anxious (p=.001). Further, their anxiety as measured by the Taylor Manifest Anxiety Scale was significantly reduced (p=.01).

Better Quality Care

A study by Jackson, Bradham and Burwell (1978) examined 31 parents who agreed to stay with their child in hospital. Parents were surveyed upon admission and three days later to determine how they wanted to participate. Their responses were recorded in the care plan. It is suggested by the findings that parents felt more comfortable with medically related activities and showed more independence in child care three days after admission, showing evidence of learning and reduced stress. Further, 23 of the surveyed parents stated they were 'very satisfied' and the remaining eight stated they were 'satisfied' with the care. The small sample size and limited detail in the reporting of results suggest limited applicability of these findings.

Sainsbury, Gray, Cleary, Davies, and Rowlandson (1986) studied 32 families to determine the effectiveness of care-by-parent units. In response to a questionnaire, 100% of parents reported being grateful for the opportunity to participate. All parents reported feeling that their children benefitted from their involvement by being more settled and content.

Cleary, Gray, Hall, Rowlandson, Sainsbury, and Davies

(1986) performed a study of the effects of parent care in hospital on the lives of child patients. The researchers made 4225 observations of patients admitted to a 14-bed pediatric unit over a one week period. Findings suggested that children cared for by parents spent far less time awake alone, cried less, and slept less than those nursed unaccompanied. Children cared for by their parents were observed to interact with their parents in 90% of social contacts.

A recent study by Styba, Elaschuk, Jesse, and Cote (1992) confirmed that parents expressed a high degree of satisfaction with being able to care for their children in hospital. Responses to a questionnaire about parents' presence on a pediatric care-by parent unit found that 99% of parents (n=95) stated they would come back to the care-by-parent unit or recommend the unit to others, and 95% reported feeling comfortable with their child care responsibilities.

Weinstein, Faust, Mckee and Padman (1992) studied the effect of a family-centred care program on six-month to 17-year old severely asthmatic children and their families. This program focused on the child's and family's adaptation to severe asthma and the development of family-specific interventions to promote compliance with treatment regimens. It was shown by the results that 44 children admitted consecutively achieved a 93% reduction in days in hospital (p<.001), an 81% reduction in emergency care (p<.01), and "a significant reduction in corticosteroid bursts and improvement in" forced expiratory volume (p. 66).

Organizational Effects

Reduced Costs

Robinson, Shah, Argue, Kinnis, and Israels (1969) found that many more children (30%) than previously thought could be safely placed in parent-care environments while in hospital. Results from this study also show apparent savings "in one quarter of the hospital beds per year" based on earlier discharges and other "economic advantages" (p. 876). A study by Vermillion, Ballantine, and Grosfield (1979) concurred that "the parent care unit costs only 70% of the cost of a routine inpatient bed and thus appeals to advocates of cost containment and efficient utilization of hospital staff" (p. 321). They also found that the parent care unit enabled parents to overcome their fears of inadequacy and to develop expertise in the management of children's health care needs. Caldwell and Lockhart (1981) also found significant cost savings and a high level of parent satisfaction by instituting parent-care units. Evans

and Robinson (1983) found that average costs of patients treated on a care-by-parent-unit compared to similar patients treated in the inpatient nursing unit demonstrated considerable savings. It must be noted that all of these studies that demonstrate cost savings are performed on parent care units. Although this form of care incorporates aspects of family-centred care, it is not the only setting in which family-centred care takes place in hospitals. As a result, assessment of parent care units may not be the best way to measure the actual costs of implementing institution-wide family-centred care.

Job Enhancement

In a previously described study by Sainsbury, Gray, Cleary, Davies, and Rowlandson (1986), nurses were asked to respond to a questionnaire on their feelings about a new care-by-parent unit. Ninety-four percent or 30 out of 32 nurses indicated that their relationships with the parents were better and that they enjoyed their teaching and supervisory roles more in the care-by-parent unit than when they practiced in the traditional method. The author suggested that this indicates that the nurses' roles were enhanced and their job satisfaction increased. However, limited data is provided to support these assertions, and the tool is not described.

Most of the reviewed studies have not explicitly defined family-centred care and none used the family-centred care framework of the ACCH. In spite of this and other specified limitations, incorporating the family into the care of the pediatric client has been repeatedly demonstrated as effective. Effects include reduced maternal deprivation, reduced separation anxiety, improved health, enhanced learning, reduced stress, improved quality of care, reduced costs, and job enhancement.

Barriers to Family-Centred Care

In the research literature, the barriers to family-centred care are also well recognized. These include perceptions, education and knowledge, staff position and experience, organizational setting, time and personal availability, role negotiation and communication, costs, and parental and marital status. Again, many of the studies reviewed neither explicitly define family-centred care nor use the framework of the ACCH. However, all reviewed studies may be considered to contain elements of family-centred care.

Perceptions

Rosenbaum, King, and Cadman (1992) surveyed 88 senior clinicians and administrators in Ontario children's ambulatory treatment centres. They also surveyed 213 parents from organizations concerned with families of disabled children. Respondents were asked to rate in order of importance 22 components of care, such as "education/information", "advice on development", and "family-centred approach" (p. 105). It is suggested by the research findings that although the family-centred care component was highly rated by parents, it was less valued and thus infrequently offered by health-care professionals.

Knafl, Cavallari, and Dixon (1988) studied family-centred care activities by surveying 62 families of children undergoing short-term hospitalization and 47 pediatric nursing staff. While believing themselves to be practicing family-centred care, it was suggested by the findings that all nurses were focused on the child rather than the family. The nurses saw themselves as "giving information, teaching, supporting patients, and supporting parents" (p. 292). In contrast, the nurse was viewed by 45% of parents as giving information, 40% of parents as teaching, 33% of parents as supporting the child, and 14% as supporting the parents.

In a qualitative study by Berman (1991) 22 nurses were surveyed about their beliefs about family-centred care. Although 95% of the nurses expressed explicit support for the concept of family-centred care, some of their beliefs and practices suggested otherwise. For example, while 45% of nurses studied trusted parents to do tasks such as monitor the child's fluid intake and output, 55% believed that these tasks should not be delegated to parents.

Bruce (1992) concurred with these findings in a study of 147 registered nurses' perceptions and practices of family-centred care. "The nurses surveyed in this study reported that their everyday work did not match their perceptions of the activities necessary to provide family-centred care" (p. 41). Their total scores on the 'current practice' scales which measured the nurses' ratings of the family-centred care items provided in their everyday practice were significantly lower than were the scores on the 'necessary' scales which measured the nurses' ratings of the family-centred care items considered necessary in practice ($p=.000$). These scores were measured on a 5-point Likert scale and represent an average mean of 3.2 and 4.2 for each total scale respectively. Further, the nurses agreed with the essential elements of family-centred care; however, many did not see some aspects of care as nurses' work. For example, only 46% of the nurses surveyed believed

that all the elements of family-centred care constituted nurses' work. Elements of family-centred care such as "sharing information" and "developmental needs" were rated as nurses' work by 61% and 59% of respondents respectively. Further, although respondents indicated a reasonable knowledge of family-centred care, they reported that they were often unable to incorporate this knowledge into their practice. The researcher found that health-care professionals perceived that they performed family-centred care significantly less in their practice than they considered necessary. Bruce suggested that the health-care professionals' knowledge of family-centred care, institutional supportive measures, and perceptions of their roles in caring for families influence the implementation of effective family-centred care in a variety of settings.

McBride, Brotherson, Joanning, Whiddon and Demmitt (1993) performed a qualitative study of 15 families' and 12 professionals' perceptions of the implementation of family-centred services in early intervention programs. Fourteen professionals consisting of an occupational therapist, a social worker, and 12 childhood special educators took part. Findings from semi-structured interviews indicated that professionals had an understanding of the change in focus from child to family; however, incongruence was found to exist between family-centred attitudes and actual practice. This agrees with other previously cited research findings.

Robinson (1987) performed a qualitative study designed to explore parents's views when their chronically ill children were hospitalized. It is suggested by the findings that unacknowledged discrepancies in perceptual viewpoints may cause the relationships between family members and professional health care providers to become adversarial. This situation "negatively affects both the effectiveness of care and perceived satisfaction with care" (p. 181).

Thornes (1985) reported on a study of 244 intensive, surgical and special care baby units. The survey consisted of a postal questionnaire, visits and detailed interviews with 13.5 percent random sample of units. The response rate was 90% on the postal questionnaire. Although apparently a thorough study, the reporting of visit and interview results is more anecdotal than statistical. The researcher reports that "there is often a clear discrepancy between nurses' perceptions of parents' abilities to perform procedures alone and parents' perceptions of their own abilities" (p. 20). Webb, Hull and Madeley (1985) echoed this finding in a study of 80 parents and 54 pediatric staff. It is suggested by the researcher that "in most instances the pediatric staff thought that the parents could do more than they did, but parents thought that they could do even more than the staff thought (p. 177).

Bailey, Palsha, Simeonsson (1990) examined the extent to which 142 early interventionists felt competent in working with families, valued family roles, and were concerned about changing to family-centred practices. Surveyed subjects included educators, physical therapists, occupational therapists, speech/language pathologists, social workers and nurses. The typical professional endorsed 54.3% of their most valued roles as family roles. Nearly half (48%) rated the majority of most important roles as family related and 22% rated an equal number of child and family roles. Thirty percent endorsed a majority of child roles as their most valued, suggesting inconsistency in the practice of family-centred care activities.

Recent studies by Latter, Clark, Wilson-Barnett and Maben (1992) and Young (1992) also emphasized perceptions. Latter et al. (1992) studied 142 British acute care nurses not limited to the pediatric setting. The researchers found that 'patient education' and 'information giving' were felt to be occurring on a greater number of wards and significantly more frequently than 'encouraging patients and their families to participate in care'" (p. 164). Young (1992) in a historical study of changing attitudes towards families of hospitalized children found that "pediatric nurses, in particular, were slow to encourage family visiting and participation in care" (p. 1422).

In relation to perception, Porter (1979) studied the effect of professional role conception versus employee role conception in influencing 353 pediatric nursing and medical employees' implementation of family-centred care. Professional role conception encompassed such factors as "concern for the client", "competence based upon knowledge and skills", and "participation in decision making", while employee role conception was determined by factors such as "respect for administrative superiors", "adherence to official rules and procedures", and "competence based on experience" (p. 330). She found a positive, but weak relationship between professional role conception and likelihood of practising family-centred care. Further, the more inclined the individual was toward the employee role, the less likely the person was oriented to practising family-centred care.

Education and Knowledge

Level of Education

Supplementary findings from Porter (1979) suggested that respondents with masters' degrees tended to be least oriented to the employee role and those with diplomas or associate degrees tended to be most oriented, suggesting

that master's prepared staff were most oriented to practicing family-centred care. Among subgroups, the higher a nurse advanced in a professional career in terms of education and experience, the more oriented the nurse was to family-centred care.

Gill (1987a) studied attitudes of 273 staff nurses, head nurses, and nurse supervisors toward parent participation in pediatric care. It was indicated by the results that master's degree prepared nurses had significantly more accepting attitudes than did nurses with diplomas, associate degrees or bachelor's degrees in nursing ($p<.05$). This indicates that educational influences can alter perceptions and acceptance of family-centred care activities such as parent participation in care. Gill (1987a) suggested that "inservice and continuing education can assist nurses, physicians, and other health care personnel to explore...and examine the factors that may be influencing their attitude toward and behaviour with parents" (p. 150). These findings support previous findings by early researchers (Dunn, 1979; Siedl, 1969). Siedl found that nurses with higher education had increased support for parent participation. Dunn (1979) also found that nurses with less than a bachelor's degree demonstrated decreased support for parent participation in hospitalized child care. Further, a study by Humphry, Gonzalez and Taylor (1993) of 340 occupational therapists found that respondents who were not in direct service and those with degrees beyond a baccalaureate tended to have more positive attitudes about working with families.

Educational Content

Cochrane, Farley, and Wilhelm (1990) surveyed 73 educational programs with infancy specializations. Eight disciplines were studied and included nursing, nutrition, occupational therapy, physical therapy, psychology, special education, speech and language pathology, and social work. Faculty representatives were administered a questionnaire requesting information about the amount of education received in infant and family assessment and intervention and any plans for "increasing infant-family focus in the future" (p. 373). In baccalaureate programs, 97% of respondents perceived that students received adequate preparation with infants compared with only 36% with families. Ninety-two percent of master's program respondents perceived that students received adequate preparation with infants compared with only 23% with families. Eighty-seven percent of respondents indicated a need for training and educational materials for working with infants' families. It is suggested by these findings that lack of family-related content in educational curricula and

training materials pose barriers to the practice of family-centred care.

Bailey, Simeonsson, Yoder and Huntington (1990) concur with these findings. Surveys were conducted to determine the extent to which entry-level students in eight disciplines receive academic preparation and clinical experiences to provide services to infants and toddlers with disabilities and their families. Disciplines surveyed included nursing, nutrition, occupational therapy, special education, social work, special education, and speech and language pathology. The survey measured the mean number of clock hours of classroom instruction in six content areas. In 'normal and abnormal infant development', speech and language pathology scored highest at the undergraduate and master's level. In 'infant assessment and intervention', occupational therapy scored highest at the undergraduate level and speech and language pathology at the master's level. In 'family assessment and intervention', nursing scored highest at the undergraduate level and social work at the master's level. These three categories recorded the most clock hours for all disciplines. Other categories included 'interdisciplinary team process', 'case management' and 'values and ethics'. It was suggested by the findings that although considerable variability was found across disciplines, the average student receives little specialized information or practical knowledge relative to either the infancy period or to working with families.

Professional Discipline

In Porter's (1979) study, physicians had the lowest orientation to family-centred care and concern for the client ($p=.000$). Porter stated that "the image of physicians as traditionally focused on pathological conditions with the patient as the unit of medical care seemed to be further supported by the present findings" (p. 334).

In a previously described study by Bailey, Palsha, Simeonsson (1990) (see 'Perceptions'), 142 early interventionists were surveyed. In general, nurses and social workers scored higher than did educators and other health-care professionals on several dimensions of family-centred care. Further, for all the health-care professionals, ratings of skills in working with families were significantly lower than ratings of skills in working with children ($p<.03$).

Marvel and Morphew (1993) studied 251 videotaped resident-patient interviews to determine the level of family involvement in medical education and practice. This study

was not limited to pediatric residents and physicians. It was shown by the results that residents asked about family issues with individual patients or spoke directly to family members about medical concerns in 41% of interviews; however, planned family conferences or emotional support of family members seldom occurred. Attending physicians inquired about family information in only 6% of the one-on-one teaching consultations with residents. The researchers suggest the need for increased medical faculty development efforts in the area of family involvement.

Results from studies performed by Brown and Ritchie (1989 & 1990) suggest other barriers to effective family-centred care in practice. In a study of 25 pediatric nurses' descriptions of satisfying and dissatisfying relationships with parents of hospitalized children, results suggested that either the nurses did not have the knowledge of communication skills, conflict management and family-centred care to provide therapeutic, goal-oriented care for parents, or had difficulty utilizing that knowledge in practice (Brown & Ritchie, 1989). A second group of 25 pediatric nurses were studied to determine their perceptions of parent and nurse roles in caring for hospitalized children. Results indicated that often the nurses' need for control influenced the psychoemotional care provided for parents (Brown & Ritchie, 1990).

Bailey, Buysse, Edmondson and Smith (1992) studied 237 health-care professionals' perceptions of the current status of family involvement in early intervention programs in four American states. The health-care professionals consisted of teachers, therapists, psychologists, social workers, program administrators and agency administrators. Ratings of typical and ideal levels of family involvement are found to present substantial and highly significant differences ($p<.0001$). In identifying barriers to family involvement in early intervention programs, 36% of respondents identified family barriers such as lack of knowledge or skill. In contrast, only 15% mentioned professional barriers such as lack of knowledge or skills. The authors conclude that "professionals perceive a substantial discrepancy between how they currently involve families in early intervention programs and how families ideally should be involved" (p. 307).

Overall, education and knowledge have demonstrated effects on perceptions and practice of family-centred care in the areas of educational level, educational content, and professional discipline.

Staff Position and Experience

It is indicated by further findings from Porter's (1979) study (see 'Perceptions' and 'Education and Knowledge') that health-care professionals in the administrative group composed of department heads, supervisors, and head nurses were more concerned with loyalty to the public than with family-centred care issues (p=.007-.01). In contrast, Gill's (1987a) study (see 'Education and Knowledge') of 273 staff nurses, head nurses, and nurse supervisors found that supervisors had significantly more accepting attitudes than did other nurses (p<.01). Gill's findings are again supported by earlier research (Dunn, 1979; Siedl, 1969). Siedl (1969) found that nurses with administrative positions had more accepting attitudes toward parent participation. Further, Dunn (1979) found that nurses under 25 and over 38 years of age, nurses with less than a bachelor's degree and nurses spending less than 25% and more than 75% of their time in direct patient care demonstrated decreased support for parent participation in care.

A study by Bailey, Buysse, Smith and Elam (1992) focuses on the effect of experience on perceptions of incorporating the family into care. The article describes the perceptions of parent participation in a workshop designed to help professionals working in early intervention programs for young children with disabilities become more family-focused in their work. Two workshops were held, one in which parents were invited to attend along with professionals and one attended only by professionals. It is indicated by the results that parent presence influenced professionals' perceived need for increasing parent participation in programs. Parents and professionals who experienced parent presence were positive about the experience and professionals who attended the workshop without parents felt strongly that parents should have been there.

Organizational Setting

Porter (1979) (see 'Perceptions', 'Education and Knowledge' and 'Staff Position and Experience') also found that subjects who worked in pediatric wards were distinctly oriented to family-centred care while those in private medical clinics and public health departments were consistently found to be least oriented. Health-care professionals' perceptions were found to indicate the likelihood of practising institution-centred care as opposed to family-centred care.

Supplementary findings of Gill (1987a) (see 'Education

and Knowledge' and 'Staff Position and Experience') indicate that subjects who worked in one of two specific hospitals had more positive attitudes toward parent participation than did other subjects $p<.05$). Although an environmental link is recognized between attitude and parent participation, Gill (1987a) does not suggest reasons or describe institutional differences. Interestingly an earlier study, which supports Gill's findings, suggests that if the charge nurse on a ward was supportive of parent participation, the nurses on the ward would have a correspondingly higher acceptance level (Siedl, 1969)

It is indicated by Knafl, Cavallari and Dixon's (1988) study (see 'Perceptions') that "the work of the pediatric nurse was also influenced by the general way in which nursing care was organized on the unit" (p. 291). The researchers suggest that primary nursing care, which recognizes the nurse's professional expertise, is most suitable to the practice of family-centred care.

Bailey, Buysse, Edmondson and Smith (1992) (see 'Education and Knowledge') study 237 health-care professionals' perceptions of barriers to family involvement in early intervention programs, also found that 35% of respondents mentioned systemic barriers such as administrative policies or lack of resources.

In relation to physical barriers in the organizational setting, a study by Thornes (1985) (see 'Perceptions') documents that many pediatric units "do not provide even simple facilities that might add to the comfort and reduce the stress of parents who may spend many hours in the unit sharing nursing care" (p. 20). Thornes (1983) also performed an earlier study of the physical barriers to parental access in children's wards. It is shown by the results of a questionnaire that in 250 out of 887 wards surveyed (28%), children were nursed in adult wards with inadequate facilities for parents. Parental access to children was denied on operating day by 36 wards and "several banned parents for 36 hours" (p. 191). However, most of the wards surveyed (89%) could provide some sort of overnight accommodation for parents.

Time and Personnel Availability

A qualitative study performed by Hayes and Knox (1984) involved interviews with 40 parents of hospitalized children with long-term disabilities. The researchers wanted to explore "parents' perceptions of health-care workers' roles" (p. 334). It is suggested by the findings that parents' perceive health-care professionals as having difficulty making themselves available to families. Hayes and Knox

(1984) also found that "parental stress is attributable to the space between health care workers...and parents" (p. 333).

Mahoney and O'Sullivan (1990) surveyed speech pathologists, occupational therapists, physical therapists, social workers, nurses, and psychologists to examine the degree to which early intervention activities currently focus on the family. Forty percent of the sample reported spending no time with families during a typical week. Respondents reported successfully achieving goals set for many of their families, yet they also reported insufficient time for family services.

Park (1991) performed a qualitative study of parents' experiences during the hospitalization of their children. The researcher discussed parents' awareness of inadequacies in their child's care. While noticing that nurses are very busy, parents expressed anger at being ignored as a source of information and assistance. All of the parents also spoke of doctors' and nurses' lack of respect for parents' opinions.

Humphry, Gonzalez and Taylor (1993) surveyed 340 occupational therapists to determine extent and manner in which they work with families. It is indicated by the results that respondents identified time and scheduling difficulties as the biggest issue affecting their involvement with families of their clients.

Role Negotiation and Communication

Results from studies by Ogilvie (1990) and Callery and Smith (1991) also suggest that nurses have difficulty making themselves available to families. Ogilvie (1990) performed a qualitative study of nine families to explore the parental experience when a child is hospitalized for surgery. It was suggested by the findings that parents perceived nurses as having insufficient time to spend with individual patients or families. Suggestion is made for nurses to negotiate roles with families. Callery and Smith (1991), in a study of role negotiation between nurses and the parents of hospitalized children concur with this finding and emphasize that role negotiation is essential to effective family-centred care.

Congruent with these findings, Algren (1985) developed a questionnaire asking 20 parents of hospitalized children about "what the parent has been asked or told about their role" and "whether they would prefer to perform the task or have the nurse do it" (p. 7). It was shown by the findings that although the majority of mothers prefer to perform many

child-care activities, 60% of mothers reported that they had not received any communication from staff regarding their role with their child, and 70% stated that the nursing staff had not explained the role they could or should assume.

Saylor, Elksnin, Farah and Pope (1990) performed a study of the types of procedures that could be useful in maximizing the participation of families in early intervention programs for special-needs infants, toddlers, and preschoolers. Twenty-nine techniques for maximizing participation of families were rated by 64 early intervention professionals and 29 mothers of high-risk children and toddlers. Verbal praise and encouragement, written and resource materials were highly rated by the professionals, whereas mothers were significantly more likely to endorse tangible reinforcement and logistical support such as monetary rewards ($p<.0001$), social encouragement ($p<.01$) and mail reminders ($p<.01$). Interestingly, professionals reported that tangible reinforcement was seldom used and that they did not expect such techniques to be useful. These discrepancies suggest a communication gap between professionals and parents that must be addressed if family-centred care is to be implemented successfully.

Overall, these studies reflect communication gaps between professionals and families in both the hospital and community settings.

Costs

Economic constraints have been suggested as barriers to effective family-centred care. Mahoney, O'Sullivan and Dennebaum (1990), in a follow-up study of 503 mothers of birth to six-year old handicapped children in early intervention programs, found that "the need for family services was greater than that currently being received" (p. 133). Gunn and Nightingale (1989) reviewed services offered in the neonatal and obstetric units of a hospital in New Zealand. Results suggest that 61 extra full-time staff were needed to reduce the workload and enable the staff to practice family-centred care. The "policy of no increase of financial resources [which] must result in a reduction of services" prevents family-centred care from becoming a reality (p. 139).

Parental and Marital Status

Interestingly, Porter (1979) found that health-care workers without offspring were more oriented to family-centred care and the professional role than were subjects with offspring. In contrast, Gill (1987a) found that

subjects who were married or parents had more positive attitudes toward parent participation than other subjects. Siedl (1969) also found a relationship between being a parent and support of parent participation in care of hospitalized children.

In summary, while family-centred care has been shown to improve health, enhance learning and reduce stress, barriers to the practice of family-centred care by health-care professionals are many. Misperceptions of family-centred care related to lack of education or understanding are frequently cited barriers. Degree of professionalism, communication gaps and lack of skill or ability to use knowledge in practice have also been cited as problems. Health-care professionals may be affected by time constraints and difficulty making themselves available to families. Inadequate communication and lack of role definition between parents and professionals are other barriers. The organizational setting and costs also influence the practice of family-centred care. Finally, demographic variables including marital status, parental status, job position, health-care discipline and educational preparation are also cited as factors influencing family-centred care.

Summary

The benefits and barriers to the involvement of families in the care of children with special health needs are well demonstrated. These are clearly recognized in spite of the lack of research that specifically utilizes the family-centred care framework of the ACCH. Only one study utilized the ACCH family-centred care framework (Bruce, 1992) and many of the studies on family involvement were not performed in the pediatric health-care setting. There is a clear need for research using the family-centred care framework in the pediatric setting.

Discrepancies are noted throughout the literature. Cost is recorded as both a benefit and a barrier to the incorporation of family-centred care, indicating a need for rigorous research. In addition, staff position and parenting experience may or may not influence the acceptance of family-centred care in practice.

Perception clearly has an effect on health-care professionals' practice of family-centred care. However, the relationship between perception and other described barriers is unclear and needs to be examined. The many difficulties experienced by staff in practicing family-centred care also suggests a need for further study. It must be determined whether staff perceive family-centred

care according to the elements described by the ACCH. If perceptions are incorrect then this becomes a barrier to practice. If perceptions are correct and health-care professionals are still unable to practice family-centred care, the question 'why?' must be asked. Is this difficulty related to health-care professionals' educational level, experience, organizational setting, time constraints, or costs that lead to understaffing? Is it related to a lack of education about the various skills needed to practice family-centred care such as communication and role negotiation? The relationship between perceptions about family-centred care and practice must be determined to facilitate the incorporation of family-centred care into the clinical setting.

CHAPTER III

METHOD

Research Design

This study is descriptive in nature and involves surveying pediatric health-care professionals at the Alberta Children's Hospital of Calgary, Alberta utilizing a questionnaire specifically developed to measure perceptions and practices of family-centred care (Bruce, 1992). This approach is appropriate to the purpose of this study since little is known about the perceptions and practices of family-centred care by pediatric health-care professionals (Brink & Wood, 1989). Relationships between the independent demographic variables and the dependent variables of perceptions and practices of family-centred care were also examined.

This study represents part of a multi-site survey. The research is also conducted by Beth Bruce, MN, Research Associate, at the Izaak Walton Killam Hospital for Children in Halifax, Nova Scotia and by Christine Dennis, MN, Clinical Nurse Specialist, at the Children's Hospital of Western Ontario, in London, Ontario.

The Sample

The population of interest is health-care professionals employed in full-time or part-time positions at the Alberta Children's Hospital of Calgary, Alberta (N=696). This population included those employed in staff, education, and management positions. The sample (n=500) was stratified by profession to include child life specialists, nurses, nutritionists, occupational therapists, pharmacists, physicians, physiotherapists, psychologists, respiratory therapists, social workers, and speech and language pathologists and audiologists.

Subjects for the sample were selected using stratified systematic sampling with random start (Palys, 1992). The names and addresses of all health-care professionals were obtained from the Alberta Children's Hospital Nursing Resources and Payroll Departments. A list of the health-care professional population was prepared, and individuals separated by their professional group. Nurses accounted for 439 and all other health-care professionals accounted for 257 of the total population. The breakdown of the non-nursing professionals included child life specialists 11, nutritionists 10, occupational therapists 26, pharmacists 13, physicians 42, physiotherapists 37, psychologists 29, respiratory therapists 10, social workers 33, and speech and

language pathologists and audiologists 46. Because of the small sizes of the non-nursing professional groups, these total populations were surveyed. The nursing professional group's list was alphabetized and randomly sampled at a ratio of 243/439. In short, 243 nurses were randomly sampled and 257 non-nursing professionals were surveyed as total populations.

The Family-Centred Care Questionnaire-Revised (FCCQ-R) (Bruce, 1993) (Appendix B) was provided to a sample of 500 Alberta Children's Hospital health-care professionals and the final sample size was determined by the number of responding subjects. In consultation with the Thesis Committee, the resultant sample was time-limited to include those participants who responded by June 8, 1994. Casual staff and professional staff on leave of absence for any reason were excluded from the study. Upon return of the questionnaires, subjects who failed to respond to the demographic questions and/or had ≥10% missing data were excluded from the analysis of data.

External and Internal Validity

Brink and Wood (1989) indicate that the "ideal sample for a descriptive design is either a total available population or a sample drawn by means of probability sampling techniques from a target population" (p. 127). Both of these techniques were used in order to ensure generalizability or external validity in the description of population characteristics. The objective of descriptive studies is to describe the variables and look for significant relationships among the variables. However, attempts are not made to draw conclusions about the causal relationships from the data. Rather, hypotheses are formulated from statistically significant relationships, and these relationships are later tested in more controlled studies from which causal relationships might be developed (Brink & Wood, 1988). As such, Brink and Wood (1989) indicate that "internal validity is not an issue in descriptive designs because no attempts are made to examine causal relationships between variables" (p. 127).

Data Collection

Data were collected by surveying 500 subjects from the Alberta Children's Hospital. The data included responses to the FCCQ-R, a 45-item questionnaire developed in a previous study, an open-ended question sheet, and a demographic data sheet.

The Alberta Children's Hospital is a well-established tertiary-care facility that serves children and families

from southern Alberta, southeastern British Columbia, and southwestern Saskatchewan. It is the only self-contained pediatric tertiary-care centre in Alberta and one of three in Western Canada. The Alberta Children's Hospital provides the excellent environment to access a variety of health-care professionals who deal exclusively with children and families. It is also committed to a philosophy of family-centred care (Appendix C).

The researcher introduced the study at a series of meetings at the Alberta Children's Hospital. The first meeting was with the Director of Nursing, a hospital nurse researcher and a nurse educator. Logistical details were discussed and a hospital sponsor was assigned to the research. The study was presented at a second meeting of department directors and a third meeting of the entire nursing executive. Details were finalized such as obtaining a letter of support from the Director of Nursing and completing the hospital's administrative checklist for research projects. The researcher was initially informed that unofficial approval had been obtained from the Chair of the Alberta Children's Hospital Research Committee and that institutional ethical approval was not needed because of approval obtained from the University of Alberta Thesis and Ethical Review Committees. However, the institutional Research Committee reconsidered and the protocol was again reviewed and followed by official approval on February 28, 1994 (Appendix D). The protocol was forwarded to the Alberta Children's Hospital Conjoint Ethics Committee and final approval was obtained on March 21, 1994 (Appendix E). This enabled the study to commence on Tuesday, March 22, 1994. Prior to commencement, an announcement about the study (Appendix F) was placed in the hospital newsletter, and posted flyers (Appendix G) and information bulletins (Appendix H) were circulated throughout the hospital.

All subjects were reached through the hospital mail service. The first of three mailouts included a covering letter (Appendix I), the questionnaire (Appendix B), an addressed return envelope, and a postcard (Appendix J). The letter explained the study, emphasized the voluntary nature of participation, and identified the time frame and method for returning the completed questionnaire. The letter also assured subjects that anonymity would be maintained throughout the study and in the reporting of study findings and confidentiality would be maintained by reporting only group data. The postcard instructed subjects to return the postcard separately when they completed the questionnaire or if they wished to be removed from the mailing list. This prevented subjects who responded from receiving the second and third mailouts. The second mailing was on Tuesday, April 5, 1994, two weeks after the initial mailing.

Subjects who did not return postcards received a second package containing a questionnaire, new cover letter (Appendix K), and return address label which could be affixed to the outside envelope for reuse. The final mailing was on Tuesday, April 12, 1994, three weeks after the initial mailing. Again, subjects who did not return postcards received envelopes containing a letter (Appendix L). These final two letters reiterated the statements of the initial cover letter, thanked subjects who already responded, and reminded subjects who had not responded to do so promptly. The mailing of the second questionnaires and final letters was done in anticipation of improving response rates.

Instrument

The FCCQ-R (Bruce, 1993) (Appendix B) was selected for this study as it was designed to measure health-care professionals' perceptions and practices of family-centred care. The instrument is the only current and relevant instrument available for this purpose. A related instrument, the Family-Centred Care Scale designed by Porter (1974) is neither accurate nor complete in its reflection of current practice and is insufficiently comprehensive to be consistent with the conceptual framework (Bruce, 1993).

The FCCQ-R is a revised version of a tool developed by Bruce (1993) to study pediatric nurses' perceptions and practices of family-centred care. The instrument is based on the guidelines for family-centred care that were generated by the ACCH (Johnson et al., 1992), and by the IWK family-centred care committee (Bruce, 1993). The items are distributed over nine subscales that represent each of the nine elements of family-centred care (Bruce, 1993).

Through the FCCQ-R, health-care professionals are asked to identify (1) the extent to which each of the 45 items is included in their everyday work and (2) the extent to which each item is necessary to provide family-centred care (Bruce, 1993). The responses were rated on a 5-point Likert-type scale, ranging from "strongly agree" to "strongly disagree". The category of "not applicable" also enables subjects to respond appropriately when the item cannot be performed in everyday work. The open-ended portion of the questionnaire provides opportunity for health-care professionals' to record any comments or "suggestions of what is needed to enhance family-centred care". Subjects are also asked to comment on whether or not "there is a large difference between your everyday work and what is necessary to practice family-centred care" and to describe "instances in which you become child-centred instead of family-centred in your approach to care". As

well, staff members are requested to provide demographic data including age group, years of clinical experience in the institution, professional group, education, staff position, parental status, and department.

Validity and Reliability

Content validity of the instrument has been established by a thorough review by the Thesis Advisory Committee (Bruce, 1992) and the IWK Family-Centred Care Committee. All reviewers agreed that the items represented all the "direct care issues in family-centred care...[and] that each item was relevant to family-centred care (Bruce, 1992, p. 35). Construct validity was not assessed.

The 55-item Family-Centred Care Questionnaire (FCCQ) was initially tested on 124 nursing staff in a tertiary care centre and subsequently revised to the present 45-item FCCQ-R (Bruce, 1993). Test-retest reliability for the FCCQ was .88, and for each of the subscales ranged from .60 to .88 (Bruce, 1993). The internal consistency was greater than alpha=.90 (Bruce, 1993). The instrument has been revised based on the item analysis (Bruce, 1993). Items that fell below the criterion levels of $\underline{r}$=.3 for inter-item correlations, $\underline{r}$=.5 for item to subscale correlations, or $\underline{r}$=.3 for item to total-scale correlations were examined for clarity of wording (Allen & Yen, 1979 as cited in Bruce, 1993). Those that were considered essential to the conceptual integrity of the scale were retained and reworded (Bruce, 1993). Items with item to total correlations of $\underline{r}$<.36 were deleted in those subscales with more than five items (Bruce, 1993). The revised instrument consists of 45 items distributed over the original nine subscales (Bruce, 1993).

Discussed in the chapter on findings, further psychometric testing of the FCCQ-R was done using correlation and factor analysis in this study. The internal consistency reliability coefficient of the instrument was tested utilizing Cronbach's alpha (Polit & Hungler, 1983). A factor analysis was also performed to determine how the 45 items cluster.

Pilot Test

The instrument was pretested to ascertain its clarity, freedom from bias, and time requirements for completion (Polit & Hungler, 1983). A convenience sample of eight subjects was selected, three from the Master's of Nursing program at the University of Alberta, three from the Grey Nuns Hospital Pediatric Unit, and two from the University Hospital Pediatric Department in Edmonton, Alberta.

Subjects were students or employees experienced or working in pediatric areas. Pre-test subjects were asked for feedback about the structure of the questionnaire. For example, "Do you feel that the side-by-side structure of the 'current' and 'necessary' scales encouraged you to be consistent in your responses to each scale?" or "Do you feel that the side-by-side structure enabled you to think more clearly about discrepancies between your responses to the 'current' and 'necessary' scales?" All subjects reported that the side-by-side structure encouraged greater consideration of discrepancies between the "current" and "necessary" scales, although one respondent indicated that the side-by-side structure encouraged consistency in responses. Results of the pre-testing were incorporated into the initial FCCQ-R structure (Appendix M) and the resultant FCCQ-R used in the study (Appendix B). The introductory paragraph was clarified, additional underlining was added to highlight important points, the "not applicable" category was explained and added, the definition of "staff" was elaborated, the definitions of staff and family were added to each questionnaire page to facilitate understanding, and the "current" scale heading was changed to read "everyday work". Changes to the open-ended portion of the questionnaire include the addition of two questions allowing respondents to describe why "there is a large difference between...current practice and what...is necessary" and "instances in which [they] become child-centred instead of family-centred in [their] approach to care (Appendix B).

Data Analysis

The findings were analyzed according to the subscales representing the nine elements of family-centred care, and the total scale scores. Descriptive statistics were used to provide a summary of health-care professionals' perceptions of the extent to which the key elements of family-centred care are necessary to practice family-centred care, and the extent to which these are perceived as being present in their own practice (Bruce, 1993). Content analysis was used to describe the variety of responses received on the open-ended portion of the questionnaire.

Analysis of variance techniques were used to determine the variation between professional groups. Undersampled disciplines required weighting in the analysis of data. T-tests were also used to determine whether staff and management groups differ in their ratings of family-centred care component items currently practised and those necessary for family-centred care. The effect of the independent variables of position, profession, education, age group, and years experience on perceptions and practices of family-

centred care were analyzed using regression analyses. The independent variables found to contribute to perceptions and/or practices of family-centred care were used as covariates in two-way ANOVAs. The Scheffé test was used to control for experimental error rate that increases with multiple comparisons.

Ethical Considerations

Several methods were used to ensure the protection of human subjects in this study. Subjects for the sample were selected using stratified systematic sampling (Palys, 1992) involving a combination of random sampling and total populations. The study was introduced in the hospital newsletter and accompanied by flyers and information bulletins throughout the hospital. The voluntary nature of participation in this study was emphasized as well as the inability to identify participants or non-participants. There was no way to match returned questionnaires with subjects, thus ensuring anonymity. The benefits of participation to knowledge development and the lack of harm to subjects were also addressed. Contact telephone numbers were provided for subjects to access more information about the study. Subjects also had the opportunity of preventing responses to the open-ended data sheet from being quoted (Appendix B). Confidentiality was assured by reporting only group data in the publication or presentation of questionnaire results. Further, data were analyzed and presented in a way that ensures that no individual participant is recognizable. The subjects were given the names, addresses, and telephone numbers of people they may contact with questions. Returned questionnaires were considered adequate for consent (Bruce, 1993).

CHAPTER IV

FINDINGS

This exploratory descriptive study examined pediatric health-care professionals' perceptions and practices of family-centred care using the Family-Centred Care Questionnaire-Revised (FCCQ-R). Family-centred care is described as consisting of the nine elements developed by the Association for the Care of Children's Health (ACCH) and modified by the Izaak Walton Killam Hospital for Children in Halifax, Nova Scotia (see Appendix A). The results of the statistical analysis of the data, factor analysis and content analysis are described in this chapter.

The data were entered into the computer and checked by the researcher, re-checked by the researcher and an associate, and checked again by a third person in a random selection of 10% of the returned questionnaires. Statistical Package for the Social Sciences (SPSS) was used and the data were determined to be accurately recorded.

Description of the Sample

Final Sample Size and Description of Losses

Five hundred employees were sampled from the Alberta Children's Hospital (ACH) population of health-care professionals, including 243 nurses and all 257 non-nurses. The total population numbered 696, 439 nurses and 257 non-nursing health-care professionals. Twenty-two questionnaires were unobtainable in the sampled group because of maternity leaves, sick leaves, or cessation of employment at the ACH. This left a sample size of 478. Two hundred and sixteen subjects returned questionnaires for a response rate of 45%. After inspection, 33 questionnaires were removed from the study because more than nine questions were incompletely answered. Twelve more questionnaires were removed because of incomplete demographic information. The number of usable questionnaires was 171, reducing the completed response rate to 36%. The remaining questionnaires that presented with nine or fewer incomplete responses (exclusion criteria of cases with ≥10% missing data) were adjusted by substituting variable means for the missing data. This ensured that the results of the data analysis were not altered by excessive amounts of missing data. As a result, the elimination of cases from the data analysis was done to reduce the error that may have occurred through the insertion of variable means into cases with large amounts of missing data.

The original data file consisting of 216 cases was

compared with the final data file of 171 cases by factor analyses. Factor Eigenvalues, which identify the amount of variance explained by individual factors (Ferketich & Muller, 1990), and the percent of variance explained by each factor for each file were similar reflecting very little difference between the original file and the final file (see Appendices N, O, P and Q).

Sample Characteristics and Descriptive Data

The final sample consisted of 2.9% child life specialists (n=5), 43.3% nurses (n=74), 3.5% nutritionists (n=6), 7.6% occupational therapists (n=13), 1.2% pharmacists (n=2), 6.4% physicians (n=11), 9.4% physiotherapists (n=16), 8.2% psychologists (n=14), 4.7% social workers (n=8), 11.1% speech/language pathologists and audiologists (n=19), and 1.8% others (n=3) (see Appendix R, Figure 1). Table 4.1 shows that social workers had the highest mean total scores on the perceptions scale of the FCCQ-R indicating more accurate perceptions of family-centred care. Physicians had the lowest mean total scores on the perceptions scale (See Appendix R, Figure 2). Table 4.2 shows that social workers had the highest mean total scores on the practice scale of the FCCQ-R, while pharmacists scored lowest (See Appendix R, Figure 3). Unless otherwise stated, the number of cases always totals 171.

Table 4.1

Health-Care Professionals' Perceptions of Family-Centred Care: Mean Total Scores

Health-Care Profession	Mean Score	Standard Deviation	Cases
Child Life	194	11	5
Nurse	191	17	74
Nutritionist	184	6	6
Occupat. Th.	188	11	13
Pharmacist	182	13	2
Physician	179	20	11
Physiother.	188	13	16
Psychologist	191	12	14
Social Work	195	22	8
Speech/Lang.	190	13	19
Other	192	18	3

$F=.92$, $p=.51$

Table 4.2

Health-Care Professionals' Practice of Family-Centred Care: Mean Total Scores

Health-Care Profession	Mean Score	Standard Deviation	Cases
Child Life	166	7	5
Nurse	165	20	74
Nutritionist	161	18	6
Occupat. Th.	162	19	13
Pharmacist	142	38	2
Physician	154	17	11
Physiother.	158	17	16
Psychologist	166	22	14
Social Work	177	17	8
Speech/Lang.	158	24	19
Other	164	43	3

$F=1.26$, $p=.26$

Eighty-six percent ($n=147$) classed themselves as "Staff", 10.5% ($n=18$) as "Managers", 4.1% ($n=7$) as "Education", 3.5% ($n=6$) as "Administration" and 7% ($n=12$) as "Other". The percentages total greater than 100 because subjects were free to choose more than one response.

Appendix R, Figure 4A shows the frequencies of the dichotomous variables before recoding. These dichotomous variables were recoded into one multicategoric variable which maximized the contribution of the categories with lower frequencies of response (see Appendix R, Figure 4B). Not all responses could be taken into account lest the assumption of independence be violated.

Tables 4.3 and 4.4 show that health-care professionals who classed themselves as "Other" scored the highest on both the perceptions and practice scales while "Staff" scored lowest on perceptions and practice (see Appendix R, Figures 5 and 6).

Table 4.3

Perception Scores According to Area of Employment

Area	Mean Score	Standard Dev.	Cases
Staff	188	16	140
Education	198	17	7
Manager	192	13	16
Administrat.	195	12	6
Other	205	9	2

$F=1.57$, $p=.18$

Table 4.4

Practice Scores According to Area of Employment

Area	Mean Score	Standard Dev.	Cases
Staff	162	20	140
Education	168	30	7
Manager	168	19	16
Administrat.	169	26	6
Other	186	19	2

$F=1.25$, $p=.29$

Subjects "less than 31 years of age" constituted 17% ($n=29$) of the final sample, "31-40 years of age" were 42.7% ($n=73$), "41-50 years" were 32.2% ($n=55$) and "51-60 years" numbered 8.2% ($n=14$) (see Appendix R, Figure 7). Table 4.5 shows that subjects less than 31 years of age scored highest on the perceptions scale of the FCCQ-R while subjects aged 31 to 40 years scored lowest (see Appendix R, Figure 8). Table 4.6 shows that subjects between 51 and 60 years of age scored highest on the practice scale while subjects less than 31 years of age and between 31 and 40 years of age both scored lowest (see Appendix R, Figure 9).

Table 4.5

Perception Scores According to Age Group

Age Group	Mean Score	Standard Dev.	Cases
Less than 31	193	16	29
31 to 40	187	15	73
41 to 50	191	16	55
51 to 60	190	14	14

$F=1.36$, $p=.26$

Table 4.6

Practice Scores According to Age Group

Age Group	Mean Score	Standard Dev.	Cases
Less than 31	159	18	29
31 to 40	159	20	73
41 to 50	169	23	55
51 to 60	172	17	14

$F=3.5$, $p=.016$

Subjects' reported professional pediatric experience ranged from one to 32 years. Thirty-nine percent ($n=68$) had one to eight years of experience, 38.6% ($n=66$) had nine to 16 years of experience, 14.6% ($n=25$) had 17 to 24 years of experience and 7% ($n=12$) reported 25 to 32 years of experience at the ACH and/or another pediatric setting (see Appendix R, Figure 10). Tables 4.7 and 4.8 show that subjects with 25 to 32 years of experience had higher scores on both the perceptions and practice scales (see Appendix R, Figures 11 and 12).

Table 4.7

Perception Scores According to Years of Experience

Years Exper.	Mean Score	Standard Dev.	Cases
1 to 8	191	16	68
9 to 16	188	15	66
17 to 24	186	15	25
25 to 32	197	13	12

$F=1.8$, $p=.14$

Table 4.8

Practice Scores According to Years of Experience

Years Exper.	Mean Score	Standard Dev.	Cases
1 to 8	162	20	68
9 to 16	164	20	66
17 to 24	164	24	25
25 to 32	168	25	12

F=.36, p=.79

As their highest level of education, nineteen point nine percent (n=34) reported post secondary education, 42.1% (n=72) had bachelor's degrees, 7% (n=12) had a professional specialty, 25.7% (n=44) had master's degrees and 5.3% (n=9) had doctoral degrees (see Appendix R, Figure 13). Table 4.9 and 4.10 show that subjects with professional specialties as their highest level of education scored lowest on both the perceptions and practice scales, while subjects with doctoral degrees and bachelor's degrees scored highest on the perception scales respectively (see Appendix R, Figures 14 and 15).

Table 4.9

Perception Scores According to Highest Level of Education Obtained

Education	Mean Score	Standard Dev.	Cases
Postsecond.	185	17	34
Bachelor's	192	14	72
Specialty	177	18	12
Master's	192	14	44
Doctorate	195	10	9

F=4.1, p=.0036

Table 4.10

Practice Scores According to Highest Level of Education Obtained

Education	Mean Score	Standard Dev.	Cases
Postsecond.	163	19	34
Bachelor's	165	20	72
Specialty	153	21	12
Master's	164	21	44
Doctorate	164	27	9

$F=.87$, $p=.48$

Finally, 65.5% ($n=112$) reported being parents. Descriptive statistics revealed that parents and non parents had very similar scores although non parents had higher scores on both the perceptions and practice scales (see Tables 4.11 and 4.12).

Table 4.11

Perception Scores According to Parental Status

Parent	Mean Score	Standard Dev.	Cases
Yes	188	15	112
No	192	17	59

$F=2.25$, $p=.14$

Table 4.12

Practice Scores According to Parental Status

Parent	Mean Score	Standard Dev.	Cases
Yes	163	22	112
No	164	18	59

$F=.05$, $p=.82$

Major Findings

The total scale and subscale scores were calculated using the total sample. T-tests, ANOVAs, regressions, and chi-square tests were then performed to determine if any relationships existed between the independent variables and the dependent variables of perceptions and practice. Unless otherwise stated, statistical significance was set at $p \leq .05$.

Total Scale, Subscale and Item Scores

T-tests for paired samples were conducted on the total scale scores, both perceptions and reported practice and the subscales for perceptions and reported practice of family-centred care. According to Polit and Hungler (1983), disproportional sampling requires an adjustment to the data "in order to arrive at the best estimate of overall population values" (p. 422). As a result, weighting was used in the analysis of this data to account for the different sampling methods performed on nursing and non-nursing health-care professionals. The population proportions were calculated for nurses and non-nurses. As nurses represented 439 of 696 total staff, the nurses accounted for 63.1% of the population. This left the remaining 257 non-nurses with 36.9% of the population. The sample proportions were then calculated. Non-nurses accounted for 97 of the 171 subject sample (56.7%). Nurses accounted for 74 of 171 (43.3%). As a result, the percentages were divided to obtain weighting factors (i.e. 63.07/43.3=1.457 and 36.93/56.7=0.651). These weighting factors were then used in the analysis of data particular to the whole sample to enable generalizations to the population at large.

The mean total scale and subscale scores are presented in Table 4.13. The total possible score for the total scales is 225 and the total possible item score is 5 on the 5-point Likert scale.

Table 4.13

Perception and Practice Scale Scores

	PERCEPTION					PRACTICE				
	M	SD	ITEM MEAN	RANGE MN	RANGE MX	M	SD	ITEM MEAN	RANGE MN	RANGE MX
Total [a]	190	16	4.2	133	221	164	20	3.6	104	210
Subscale1 [b]	13	1.6	3.3	8	15	12	1.9	3	4	15
Subscale2 [c]	21	2.8	3.5	14	30	18	3.1	3	10	27
Subscale3 [d]	23	2.0	4.6	17	25	21	2.9	4.2	11	25
Subscale4 [e]	22	2.3	4.4	14	25	19	3.3	3.8	10	25
Subscale5 [f]	17	2.0	4.3	11	20	15	2.8	3.8	5	20
Subscale6 [g]	22	2.3	4.4	14	25	19	2.9	3.8	9	25
Subscale7 [h]	18	1.8	4.5	12	20	17	2.3	4.3	8	20
Subscale8 [i]	28	3.6	4.0	16	35	22	4.7	3.1	11	30
Subscale9 [j]	26	2.7	4.3	17	30	21	4.1	3.5	10	30

MN=Minimum, MX=Maximum
[a] t=17.22
[b] Family is constant, t=5.43
[c] Collaboration, t=12
[d] Individuality, t=12.5
[e] Information sharing, t=12.6
[f] Parent to parent support, t=12.3
[g] Development, t=10.7
[h] Emotional/financial support, t=10.5
[i] Health system design, t=15.2
[j] Staff support, t=15.7
(p<.001)

The item scores ranged from 1 to 5 for both the perceptions and practice scales on the FCCQ-R. Eleven items had ranges from 3 to 5 and all were from the perceptions scale. The lowest scoring items were items 4 "everyday work" (M=1.62, SD=.87) and "necessary" (M=1.52, SD=.87) which measured subjects' perceptions and practice of the second element of family-centred care or "collaboration".

Items 4 "everyday work" and "necessary" were the only reverse scored items as they were supposed to represent something other than family-centred care. The low mean item scores on items 4 "everyday work" and "necessary" suggests that the reverse scoring has limited effect. This raises questions about the reliability of the item if it was identified by respondents as representing the family-centred care element of "collaboration". The next lowest scoring item was item 34 "everyday work" (M=2.06, SD=.97) which referred to materials being available in both English and French. The highest scoring item was item 11 "necessary" (M=4.73, SD=.48). Eight items had mean scores of 4.6 or above and five of the items were from perceptions subscale 3 of the FCCQ-R which measures subjects' perceptions of the importance of the "family strengths and individuality" element. Item 2 "everyday work" was the highest scoring item from the practice scale and item 2 "necessary" was one of the highest scoring items overall. This item measured subjects' practice and perceptions of the importance of "determining the level of participation...that suits the family's needs best". See Appendix S.

Relationships Between Demographic Variables and Scores on the Perceptions and Practice scales

One-way analysis of variance (ANOVA) tests were used to determine the extent to which pediatric health-care professionals perceive family-centred care to be important and the independent variables of particular health-care profession, age, years of professional experience and highest level of education obtained. Statistically significant differences were found in bachelor's prepared (see Table 4.14) and older health-care professionals (see Tables 4.4 and 4.15). The Scheffé test was used to control for experimental error that increases with such multiple comparisons. In addition, T-tests were conducted to determine if differences existed between perceptions of family-centred care and the dichotomous independent variables of parental status and measures of hospital position including staff, education, manager, administration and other. No significant differences were identified. The measures of hospital position were also combined into staff and nonstaff (cases were counted as nonstaff before staff to maximize the number of nonstaff cases, Norusis, 1992) and t-tests showed no significant differences between staff and nonstaff health-care professionals. The same tests were performed using the dependent variable of practice and no statistically significant differences were found.

Table 4.14

One-Way Analysis of Variance of Perception Scores by Highest Level of Education Obtained

SOURCE	DEGREES OF FREEDOM	MEAN SQUARES	F RATIO	F PROBABILITY
Between Groups	4	919	4.06	.0036
Within Groups	166	226		

MEAN	GROUP	
176.7	Professional Specialty	
184.7	Post-secondary	
191.7	Master's Degree	
192.2	Bachelor's Degree	*
194.5	Doctorate	

(*) Indicates significant differences

Table 4.15

T-Test for Differences Between Older and Younger Subjects on Practice Scores

AGE IN YEARS	NUMBER	MEAN	SD
Less Than 41	102	159	19
41 and Older	69	169	22

T-TEST FOR EQUALITY OF MEANS

VARIANCES	DF	T-VALUE	2-TAIL SIG.
Unequal	169	-3.16	.002

DF=degrees of freedom

The independent variables (see Appendix B demographic sheet) were entered into regression equations after dummy coding of the nominal independent variables was completed (Munro & Page, 1993). This dichotomous coding method indicates that a case belongs "to the chosen group or not" (Munro & Page, 1993, p.206). The multicategoric variables, such as highest level of education obtained and health care profession were recoded and entered into multiple regression equations as groups, leaving out one variable which served as a comparison. Simple bivariate regressions were also performed on all the variables. A collinearity was found to exist between bachelor's education and some other combination of variables from the measures of the highest

level of education obtained.

Table 4.16 shows that the variables of post-secondary education, professional specialty, physicians and staff were found to contribute significantly to perception scores in negative correlations. Responses of subjects who reported having only post-secondary education or a professional specialty as their highest level of education obtained had lower scores on the family-centred care perceptions scale. Subjects who reported their area of employment as being solely staff not violating the assumption of independence, or who were physicians contributed negatively to the variance of scores on the perceptions scale. In other words, health-care professionals who reported being physicians or staff or who reported post-secondary education or a professional specialty as their highest level of education had lower mean total scores on the perceptions scale. Subjects who reported bachelor's education as their highest level of education obtained approached significance (Beta=.14, $\underline{t}$=.06) in the 2% positive contribution to the variance observed in perception scores.

Table 4.16

The Contribution of Significant Variables to Perception Scores in the Regression Equation

VARIABLE	VARIANCE EXPLAINED (%)	B	BETA	SIGNIFICANCE OF T
Postsecond. Education	2.4	-6.08	-.156	.0411
Professional Specialty	5.2	-13.8	-.228	.0027
Physicians	3.3	-11.4	-.181	.0179
Staff	2.7	-6.56	-.163	.0333

Table 4.16 shows that age and social workers' responses contributed significantly to positive practice scores on the FCCQ-R. In other words, older health-care professionals or social workers contributed positively to scores on the practice scale. Professional specialty (Beta=-.14, $\underline{t}$=.069) approached significance in the 1.9% contribution to the variance observed in the practice scores.

Table 4.17

The Contribution of Significant Variables to Practice Scores in the Regression Equation

VARIABLE	VARIANCE EXPLAINED (%)	B	BETA	SIGNIFICANCE OF T
AGE	5.5	.68	.234	.0021
SOCIAL WORK	2.3	14.8	.152	.0465

Secondary Findings

The findings of the regression analysis were examined using the Pearson chi-square test. The negative correlations between professional specialty and perceptions of family-centred care were examined to determine which professional groups reported having a professional specialty. Nine physicians, two nutritionists, one pharmacist and one physiotherapist reported having a professional specialty as their highest level of education. The null hypothesis that professional specialty is not related to health profession was not supported using the Pearson chi-square test ($p<.00001$) (Munro & Page, 1993). The negative correlations between subjects with only post-secondary education and perceptions of family-centred care were examined to determine which professional groups reported having only post-secondary education. Thirty-one nurses and one physiotherapist reported having only post-secondary education. The null hypothesis that post-secondary education is not related to health profession was also rejected by the Pearson chi-square test ($p<.0001$) (Munro & Page, 1993). In this study, health-care professionals who reported having post-secondary education as their highest level of education contributed negatively to the mean total scores on the perceptions scale. The Pearson chi-square test also rejected the hypothesis that age is not related to years of experience ($p<.00001$).

Two-way ANOVA tests were performed using the independent variables of age, post-secondary education, professional specialty, physicians and staff against the dependent variable of perceptions to determine if any of the variance could be explained by interacting variables. Two-way ANOVAs were also performed on the independent variables of age and social work with the dependent variable of practice to examine any covariance interactions. No significant interactions were found.

The professional groups were divided into nursing and non-nursing groups and compared with total scale scores on perceptions and practice of family-centred care. No

significant differences were found.

Overall, perceptions scores were found to be statistically significantly greater than practice scores. Bachelor's education was found to be statistically significantly different from all the other education levels and approached significance in the positive contribution to scores on the perception scale. Reported post-secondary education, professional specialty, physicians and staff were found to contribute negatively to perception scores. Older subjects were also found to be statistically significantly different than younger subjects in their positive contribution to scores on the practice scale. Social workers were found to contribute positively to practice scores. Although no significant interactions were found amongst the variables, professional specialty and post-secondary education were found to relate to a particular health-care profession from the Pearson chi-square tests.

Factor Analysis

A factor analysis was performed on the 171 cases to determine how the 45 items clustered. The internal consistency of the instrument was tested using Cronbach's alpha (Munro & Page, 1993).

Initially, the perceptions and practice scales factored into 11 and 14 factors respectively. Both scales were expected to contain nine factors (Bruce, 1992). Upon forcing the scales to cluster into nine factors, the perceptions and practice factors accounted for 57% and 54% of the variance respectively. The nine factors did not cluster according to the nine subscales. Factor 1 in the cluster analysis grouped around subscale 3 "individuality" of the perception scale. The remaining factors scattered amongst the remaining subscales for both perceptions and practice (See Appendices P and Q).

The results of the internal consistency reliability test for the perceptions and practice scales and subscales are described in Tables 4.18 and 4.19. The range of acceptable alpha reliability scores is conventionally considered to be $r \geq .8$ (H. Northcott, personal communication, July 22, 1994). The total scale alpha reliability coefficients for both perceptions and practice scales are high. Subscales one "family is constant" and two "collaboration" have low alpha reliability coefficients and the remaining subscales have marginally acceptable alpha coefficients. These findings suggest that the subscale items are only moderately reliable measures of the elements of family-centred care.

Table 4.18

Perceptions Scale Internal Reliability Coefficients

SCALE	ALPHA
Total	.91
Subscale 1-Family is Constant	.23
Subscale 2-Collaboration	.52
Subscale 3-Individuality	.78
Subscale 4-Sharing Information	.67
Subscale 5-Parent Support	.65
Subscale 6-Developmental Needs	.72
Subscale 7-Emot./Fin. Support	.75
Subscale 8-Health System Des.	.70
Subscale 9-Staff Support	.76

Table 4.19

Practice scale Internal Reliability Coefficients

SCALE	ALPHA
Total	.92
Subscale 1-Family is Constant	.36
Subscale 2-Collaboration	.47
Subscale 3-Individuality	.72
Subscale 4-Sharing Information	.66
Subscale 5-Parent Support	.67
Subscale 6-Developmental Needs	.65
Subscale 7-Emot./Fin. Support	.63
Subscale 8-Health System Des.	.71
Subscale 9-Staff Support	.68

Content Analysis

The four open-ended questions at the end of the survey were examined by content analysis (see Appendix B). Fifteen subjects failed to respond to any of the open-ended questions, resulting in 201 completed surveys (response rate=93%). The original 216 cases were used for content analysis because the final data file of 171 cases did not

represent subjects who were removed from the original 216 cases. As a result, it was impossible to determine which cases should be eliminated from the content analysis. It may be assumed, however, that the content analysis sample was similar to the sample used in the analysis of data and that their responses were similar. Further, the likelihood of obtaining a richer variety of responses by using the original 216 cases was felt to outweigh the assurance of having the same sample.

Response rate varied among the four questions: Question 1 - 193/201 (96%) completed; Question 2 - 161/201 (80%) completed; Question 3 - 143/201 (71%) completed; Question 4 - 60/201 (30%) completed. Responses to Question 4, which asked subjects to "list any suggestions of what is needed to enhance family-centred care", frequently echoed the sentiments of the first three questions and was largely considered in that capacity. Other respondents to question four suggested structural improvements to the FCCQ-R.

Question 1 "Do you think there is a large difference between your everyday work and what you think is necessary to practice family-centred care? If so, why? If not, why?"

This discussion describes the statements of respondents who answered positively, negatively, or indecisively. Respondents who went into greater detail about "why" there is or is not a large difference echoed the responses many gave to question 3. As a result, these responses are discussed in the section on question 3, below.

"Yes, there is a large difference".

One hundred and eleven (58%) of the respondents answered "yes, there is a large difference". A typical positive response states: "Yes - dollars are what drive the system, not patient/family needs. To provide true family-centred care [sic] will take more money in certain areas, especially family support".

"No, there is not a large difference".

Forty-nine respondents (25%) answered "no, there is not a large difference". Typical negative responses include: "No. My experience at ACH...has been one of support for family-centred care" and "No, in this hospital we try to keep it a family-centred environment in our everyday work because we think it is necessary". Many negative respondents echoed the sentiments of positive respondents, for example: "At this point in time no. However, I am afraid that this will change with the current health care cutbacks in Alberta".

Indecisive.

Thirty-three (17%) respondents answered indecisively. A typical response deemed indecisive was "In my individual work with families, I have ample time and space to address family concerns confidentially. During outpatient clinic visits, there is little private space and opportunity to meet is limited".

Question 2: "If there are instances in which you become child-centred instead of family-centred in your approach to care, please describe."

Nine respondents (6%) indicated that they never become child-centred in practice. For example "I personally am always family centred but my program is not always so". A more common response was "These [family-centred care and child-centred care] are not interchangeable in my view. When I am child-focused...I must still take the family's perspective into account in order to maximize the success of my involvement and decrease the risk of sabotage". The remaining 94% of respondents described instances in which they become child-centred in practice.

Child's well-being at stake.

The most frequently cited instance (n=57) in which subjects reported becoming child-centred was when the "child's well-being is at stake". This involved instances of neglect or abuse, emergency or intensive care situations. Operating room professionals cited that child-centred care was frequently the norm.

Dysfunctional or absent families.

The second most frequently cited instance (n=52) of child-centred care was in cases of "dysfunctional families" or when "families are unable or unwilling to become involved". Examples included families that are unable to cope or parents who are unable to visit for geographical reasons. Subjects (n=15) also reported becoming child-centred in the approach to care in cases of "adoption, foster care or when the family is simply not involved". Many respondents indicated the strong advocacy needs of children in these situations.

Older children.

The third most frequently cited instance (n=18) when respondents reported becoming child-centred was in cases of older children. For example, in cases of "...older children who have and can express their aspirations and goals, their

concerns can supersede those of the family".

Professional judgement.

The last reason cited as being an instance in which health-care professionals become child-centred has been grouped into the category of "professional judgement" (n=10). Professional judgement occurs when the "family beliefs/values are contradictory to health/well being of [the] child - the centre needs to advocate for the child" or when the "parent upsets the child during a painful procedure". Other cited instances of professional judgement include assessments when the parent should not be present, as in cases of suspected abuse or psychological examination of the child.

Child's needs considered first.

Finally, some respondents (n=5) indicated that the "patient comes first - family requirements secondary" or that it was easier to cope with only the child's concerns. These respondents indicated that family-centred care was "not practical" as the "health care system is already overburdened" and that "psychosocial factors are of little importance". These responses suggest a lack of support, and perhaps misunderstanding of the concept of family-centred care.

Overall, most respondents that reported becoming child-centred indicated that the families' needs "would be met after the crisis" or are "considered in the context of the child".

Question 3: "Please list any suggestions of what is needed to enhance family-centred care."

These responses echoed the responses many gave to the first question of "why" there is a "large difference between your everyday work and what you think is necessary to practice family-centred care".

Financial resources.

By far, the most frequently cited suggestions or reasons for the large difference between subjects everyday work and what they thought was necessary to practice family-centred care were "financial resources" and provincial "politics" (n=60). These encompassed recent budget cutbacks that many respondents felt contributed to inadequate staffing levels and decreased staff expertise. Many respondents expressed concern that the cutbacks caused "bumping" and an "increase in part-time and casual staff"

that contributed to a decrease in expertise and continuity of care. As a result, lobbying the government or obtaining government support was suggested to enhance the practice of family-centred care.

Time.

Many respondents (n=44) reported that time constraints limited the ability to practice family-centred care. "Decreasing financial resources contribute to high census levels and inadequate staffing levels, putting time for adequately incorporating the family at a minimum".

Education.

Suggested frequently (n=40) were improvements in health-care professionals' education about family-centred care. This was recommended both at the university/college level and at the hospital level. Stronger orientations, hospital inservice programs and continuing education programs were highly recommended. Many respondents indicated that the lack of understanding and practice of family-centred care on many levels was related to lack of family-related content in educational programs. Subjects reported that the medical or acute care model limited the use and effectiveness of the family-centred care model. Some subjects (n=22) recommended improving "hospital-wide" support or "administrative support" for family-centred care and improving "multi-disciplinary coordination and communication". Other respondents (n=11) suggested "more community outreach" to move away from the medically-oriented model or an increase of "parent services or social work" services to fill the gap between subjects' everyday work and what they considered necessary to practice family-centred care.

Family participation.

Other respondents (n=34) suggested "encouraging and involving the family" as a suggestion for enhancing family-centred care. Care-by-parent units, involvement in team conferences and access to charts was recommended. Further, respondents suggested expanding the hours for treatment and increasing the flexibility of the system to accommodate families' schedules. Some recommended increasing resources for families, such as travel reimbursement or subsidized child care for siblings of children in hospital. Other recommended resources included greater access and availability of educational materials, such as videos and pamphlets for families.

Communication.

"Improving communication with the family" was frequently cited (n=18) as essential to encouraging and involving the family in setting goals and assessing the family situation appropriately. Physical barriers such as "inadequate space to communicate with family members in private" was also reported as problematic.

Overall, improved financial resources, increased staffing, more time with children and families, improved education of professionals, family participation, more resource materials, communication and physical space are suggestions to enhance the practice of family-centred care.

Question 4: "Please write any additional comments below."

Structural problems that subjects described in their responses to question four ranged from comments related to practice at the ACH to spelling corrections of the questionnaire. Many respondents (n=9) described problems responding to the questions related to the acute care and nonacute care aspects of their jobs. For example, some respondents suggested that they had difficulty responding to the questions because "some of the questions were somewhat inapplicable to the outpatient setting" or that many questions are "very dependent on setting (e.g. inpatient/outpatient) to which they are applied". Others found it difficult to answer many of the questions "due to the nonacute/acute care range of service offered within this setting". In response to item 25 which stated "direct care managers have an adequate knowledge in child development..." several respondents wanted to know what "direct care managers" were. In response to item 34 which asked if "all written material for families is available in French/English versions", several respondents indicated that the need for written materials is far greater in Spanish, Chinese, Vietnamese and other languages than French.

Summary

Health-care professionals described the degree to which the nine key elements of family-centred care are necessary to practice family-centred care as being higher than the degree to which the key elements are present in their practice. A statistically significant discrepancy was found to exist between health-care professionals' perceptions of the need for family-centred care compared with their practice of family-centred care. Perception scores of health-care professionals whose highest level of education was a bachelor's degree were statistically significantly higher than those with post-secondary, master's,

professional specialty and doctoral education. Factors contributing negatively to perception scores were post-secondary education, professional specialty, physicians and staff. Age was found to contribute positively to practice scores with subjects older than 41 years having statistically significantly greater scores than younger subjects on the practice scale. Health-care professionals who reported being social workers contributed positively to practice scores. Although no significant interactions were found amongst the variables, professional specialty and post secondary education were found to relate to the medical and nursing health-care professions respectively in the Pearson chi-square tests. The factor analysis revealed high alpha reliability coefficients for the total scale, yet relatively low subscale alphas. The content analysis described subjects' responses to the open-ended portion of the FCCQ-R and described instances when subjects reported becoming child-centred and their suggestions for improving the practice of family-centred care.

CHAPTER V

DISCUSSION

Although family-centred care has received substantial recognition as a satisfying and useful experience for children and their families, it "has not found its rightful place in health centres or among health care workers" (Porter, 1979, p. 330). Further, many health-care professionals respect and support the idea of family-centred care, but few actually put it into practice (Blumenstein, 1986; Porter, 1979). This discrepancy between health-care professionals' perceptions of family-centred care and the practice of family-centred care has been the focus of this study.

The purpose of this exploratory descriptive study was to determine health-care professionals' ratings of their perceptions and practices of the components of family-centred care (see Appendix A) at the Alberta Children's Hospital in Calgary between March 22 and June 8, 1994. Relationships between the independent demographic variables and perceptions and practice of family-centred care were also examined. Results from this research provide insight into health-care professionals' perceptions of the barriers to practising family-centred care. They also show to what degree family-centred care is practised and emphasize the importance health-care professionals attach to being able to practice family-centred care. This helps to clarify assumptions and questions about the viability of family-centred care in practice. The "dilemma of helping" (Dunst, Trivette & Deal, 1988a) is raised as a contributor to the discrepancy between health-care professionals' perceptions and practice of family-centred care.

This chapter discusses the study findings and analyzes them in relation to previous findings. Limitations and implications for practice, education and research are also examined.

Summary of Findings

Findings from this study revealed that health-care professionals described the degree to which the nine key elements of family-centred care are necessary to practice family-centred care as being higher than the degree to which the key elements are present in their practice. Health-care professionals whose highest level of education was a bachelor's degree contributed more positively to perception scores than those with post-secondary, master's, professional specialty and doctoral education. Factors contributing negatively to perception scores were post-

secondary education, professional specialty, physicians and staff. Age was found to contribute positively to practice scores with subjects older than 41 years having statistically significantly greater scores than younger subjects on the practice scale. Health-care professionals who reported being social workers contributed positively to practice scores. Although no significant interactions were found amongst the variables, professional specialty and post secondary education were found to relate to the medical and nursing health-care professions respectively in the Pearson chi-square tests. The factor analysis revealed high alpha reliability coefficients for the total scale, yet relatively low subscale alphas. The content analysis described subjects' responses to the open-ended portion of the FCCQ-R and described instances when subjects reported becoming child-centred and their suggestions for improving the practice of family-centred care.

Discussion of Findings

The findings from this study will be compared with similar results from previous research. As this study partially replicated a study by Bruce (1992) of nurses' perceptions and practices of family-centred care, the results from the present study will be compared with those of Bruce. Bruce found that perception scores were significantly higher than practice scores and that age and clinical position were significantly related to perceptions and practices of family-centred care. Nurses aged 41 to 50 had higher scores on the practice scale than the other age groups, while staff nurses had lower score on the perception scale than administrative or education nurses.

Perceptions

Perception scores were found to be statistically significantly greater than practice scores. In other words, health-care professionals reported being less able to perform family-centred care in practice than they considered necessary. This finding corresponds with findings from previous research (Bailey, Buysse, Edmondson & Smith, 1992; Berman, 1991; Knafl, Cavallari & Dixon, 1988; McBride, Brotherson, Joanning, Whiddon & Demmitt, 1993; Porter, 1979; Robinson, 1987; Rosenbaum, King & Cadman, 1992). In particular, Bruce's (1992) findings concurred with these findings in her study of nurses' perceptions and practices of family-centred care. "The nurses surveyed in this study reported that their everyday work did not match their perceptions of the activities necessary to provide family-centred care" (p. 41). Their total scores on the practice scale were significantly lower than were the scores on the perception scale. Mean item scores for the respective

perceptions and practice scales found by Bruce (M=4.2 SD=.35, M=3.2, SD=.4) were similar to mean item scores found in the study under discussion (M=4.2 SD=.35, M=3.6 SD=.4). It should be noted however that the mean item practice scores for both the subsample of nurses and the total sample were greater in this study than in Bruce's study of nurses. These findings indicate that although respondents indicated a reasonable knowledge of family-centred care, they reported that they were often unable to incorporate this knowledge into their practice. In other words, both studies support the notion that health-care professionals perceived that they performed family-centred care significantly less in their practice than they considered necessary. These findings imply a need to examine other causes than misperceptions of family-centred care to determine why health-care professionals are unable to incorporate family-centred care into practice.

Education and Knowledge

Bachelor's education was statistically significantly different than other education levels and approached significance in the positive contribution to the variance in perception scores. Post-secondary education was found to contribute negatively to perception scores. In other words, bachelor's educated health-care professionals had more positive perceptions of family-centred care while the post-secondary educated health-care professionals had more negative perceptions of family-centred care. These findings agree in part with Porter's (1979) finding that respondents with diplomas or associate degrees were least oriented to practicing family-centred care. Dunn (1979) also found that nurses with less than a bachelor's degree had decreased support for parent participation in care. In contrast, other researchers found that master's degree prepared nurses had significantly more accepting attitudes toward families than did nurses with diplomas, associate degrees or bachelor's degrees (Gill, 1987a; Humphry, Gonzalez & Taylor; 1993; Porter, 1979).

Scores from subjects who reported being physicians or who had a professional specialty as their highest level of education were found to contribute negatively to perception scores. This supports Porter's (1979) finding that physicians had the lowest orientation to family-centred care and concern for the client. Porter stated that "the image of physicians as traditionally focused on pathological conditions with the patient as the unit of medical care seemed to be further supported by the present findings" (p. 334). Marvel and Morphew (1993) also found that attending physicians rarely inquired about family information. The researchers suggested the need for increased medical faculty

development efforts in the area of family involvement.

Social workers were found to contribute positively to practice scores. Bailey, Palsha, Simeonsson (1990) found that nurses and social workers scored higher than did educators and other health-care professionals on several dimensions of family-centred care. Bailey, Simeonsson, Yoder and Huntington (1990) found that nursing and social work scored highest for classroom instruction in 'family assessment and intervention'.

Experience

This study found that increasing subject age positively contributed to scores on the practice scale. In particular, subjects older than 41 years of age were found to have statistically significantly greater scores than the combined other age groups. As expected, age was also found to be related to years of experience. In accordance with these findings, Porter (1979) found that the higher a nurse advanced in a professional career in terms of education and experience, the more oriented the nurse was to family-centred care. Bruce (1992) also found that older subjects between the ages of 41 to 50 had higher scores on practice scale of the family-centred care questionnaire. In contrast, Dunn (1979) found that nurses over 38 years of age demonstrated decreased support for parent participation in care. In spite of Dunn's (1979) findings, the results of this study support the assumption that the experience that comes with age positively contributes to the ability of health-care professionals to incorporate family-centred care in practice.

Staff Position

This study found that health-care professionals in staff positions as opposed to education or management positions scored more negatively on the perception scale. This corresponds with Bruce's (1992) finding that subjects who were in staff position had lower perception scores. This also agrees with previous findings that administrators, supervisors or subjects who were not in direct service have more positive attitudes about working with families (Dunn, 1979; Gill, 1987a; Humphry, Gonzalez & Taylor ,1993; Siedl, 1969). In contrast, Porter (1979) found that health-care professionals in the administrative group composed of department heads, supervisors, and head nurses were less concerned with family-centred care issues than other groups. In spite of Porter's (1979) findings, the results of this study appear to support the assumption that health-care professionals in staff positions have less positive perceptions of family-centred care activities. This finding

is troublesome as it suggests that the staff who work most closely with families and children have the least accurate perceptions and understanding of family-centred care.

Communication

In subjects' responses to the qualitative portion of this study, the need for communication with families was recognized as an important suggestion to enhance family-centred care. This confirms results from previous research (Brown & Ritchie, 1989 & 1990). This communication problem has been referred to as being related to lack of time (Ogilvie, 1990; Park, 1991) or related to lack of communication or role negotiation skills (Algren, 1985; Callery & Smith, 1991). Communication also appeared to play a role in maximizing family participation. This finding is also supported by research (Saylor, Elksnin, Farah & Pope, 1990).

Financial and Time Constraints

Overwhelmingly, subjects cited financial constraints as barriers or challenges to the practice of family-centred care in their answers to the qualitative component of the survey. This finding supports previous findings (Mahoney, O'Sullivan & Dennebaum, 1990; Gunn & Nightingale 1989). In relation to financial constraints, many subjects felt that time constraints prevented the practice of family-centred care. This supports many previous findings (Hayes & Knox, 1984; Humphry, Gonzalez & Taylor, 1993; Mahoney & O'Sullivan, 1990; Park, 1991).

Parental Status

No differences were found between health-care professionals based on parental status on both the perceptions and practice scales of family-centred care. Porter (1979) found that health-care workers without offspring were more oriented to family-centred care than were subjects with offspring. In contrast, Gill (1987a) and Siedl (1969) found that subjects who were parents had more positive attitudes toward parent participation than other subjects.

Organizational Setting

In the qualitative component of this study organizational factors were identified as influencing the way family-centred care was practised. Some respondents cited the importance of physical space, while others suggested a need for widespread managerial and administrative support for family-centred care. These

findings are supported by previous research (Bailey, Buysse, Edmondson & Smith, 1992; Gill, 1987a; Knafl, Cavallari & Dixon, 1988; Porter, 1979; Siedl, 1969; Thornes, 1985).

Limitations

The limitations of this study are discussed in terms of the validity and reliability of the FCCQ-R with recommendations for future use. The limitations to generalizability of the study findings are also addressed.

Family-Centred Care Questionnaire-Revised

The FCCQ-R was proposed to represent the nine elements of family-centred care (see Appendix A). The factor analysis results showed that the subscales were poor to fair measures of the nine elements of family-centred care; however the overall scale had good internal consistency reliability. Responding subjects also suggested that selected items were not suited to the setting in which they worked. For example, a typical respondent stated that "some of the questions were somewhat inapplicable to the outpatient setting". Modification of this tool is recommended before future usage.

Subscales one and two which measured "family is constant" and "collaboration" should either be reworded or eliminated. Rewording would better reflect the elements being measured while elimination would change the subscale nature of the questionnaire to reflect the overall practice of family-centred care. The subscales could also be reorganized according to the factor loadings obtained from the factor analysis and future tests of internal consistency reliability could test the new structure. Items should also be reworded, in particular item four which supposedly reflects something other than family-centred care. Few subjects made this distinction and the reverse scoring of item four may have contributed to the low internal consistency reliability of subscale two. Other subjects suggested that the questionnaire posed difficulty to health-care professionals who were not nurses or who worked in outpatient or non-acute care settings. Terminology such as "direct care managers" was confusing and unfamiliar to subjects at the ACH. Further, regional cultural differences were overlooked by the questionnaire as in item 34 which asked about "written material for families is available in French/English" only. This item would better represent regional cultural differences by asking if written material is available in the "families' first language". Respondents reported a need for materials in Chinese, Vietnamese and Spanish.

The validity of the tool was partially established by responses to the open-ended portion of the questionnaire. The qualitative data essentially reflected the overall result that perceptions of family-centred care are fairly accurate yet subjects are unable to practice family-centred care as well as they would like. Recall that 58% of respondents indicated that there was a "large difference between" their everyday work and what they thought was necessary to practice family-centred care. Some of the more frequently stated reasons for this difference were "time constraints", "provincial budget cutbacks", "acute care setting" and "physical barriers".

Overall, the FCCQ-R provided the best measure of perceptions and practice currently available. Further modification will enhance the reliability and validity of this tool for future use.

Generalizability

Non-nurse subjects were from total available populations and nurses were from a sample drawn by means of probability sampling from a target population to ensure generalizability or external validity in the description of population characteristics. Sampled subjects were asked to respond on a voluntary basis which may have introduced bias into the study findings. It is difficult to determine the direction of the bias; however, subjects did identify a discrepancy between perceptions and practice and most indicated that a "large discrepancy did exist". If the assumption is made that subjects who respond are subjects that are more likely to have a greater interest or knowledge of the practice of family-centred care, the results do not bear out this assumption.

The overall findings that perceptions of family-centred care are relatively positive, while the practice of family-centred care is less than desirable may be generalizable to the population of health-care professionals at the ACH. Generalizability to other pediatric facilities is less clear, given one's position on the random nature of the sampling. If one assumes that the sample obtained from the ACH was random in that the subjects sampled were any of the possible number of pediatric health-care professionals in the population that could have been working there at any given time, then the sample was random and the results are readily generalizable to other pediatric tertiary care facilities. In contrast, if one assumes that the sample obtained from the ACH consisted of total populations and samples from total populations are not random then the results are only generalizable to the ACH, and less so to other similar pediatric tertiary care facilities. The fact

that 25% of the total population of health-care professionals provided usable data for analysis gives this researcher confidence in the generalizability of findings to the total population at ACH and cautious generalizability to other similar pediatric settings.

Findings that were more specific to the health-care professions are viewed with guarded generalizability based on the smaller sizes of the subsamples. For example, the generalizability of the finding that physicians contributed to lower scores on the perceptions scale of family-centred care must be tempered by the knowledge that only 11 physicians' responses were used in the analysis of data. Further, the insertion of mean scores into the questionnaire for analysis may have introduced some bias into the results, given that the insertion of means occurred in part to account for subjects who did not perform certain aspects of family-centred care in their practice. This would pertain to subjects who did not have some specific questionnaire item in their job description. This reflects responding subjects' concern that some questionnaire items did not reflect their practice, but rather nursing or acute care practice (described above under "Family-Centred Care Questionnaire-Revised").

Implications of Findings

The perceptions and practices of family-centred care appear to be affected by education and knowledge, experience, staff position, financial and time constraints, communication, and the organizational setting. The quantitative portion of the study suggests that the "dilemma of helping" (Dunst et al., 1988a) may also influence the perceptions and practices of family-centred care. Further, the findings suggest that positive strides have been made by health-care professionals since the early days of family-centred care. A discussion of the effect of the cohort addresses these strides. The findings are then discussed in terms of the dilemma of helping, practice, education and research.

The Effect of the Cohort

A cohort has been defined as "a group of individuals who share a common experience within a defined period of time" (Woods & Catanzaro, 1988, p. 120). The cohort in this study may have been affected by the onset of family-centred care theory and practice that began in the 1970's. Indeed the first definition of family-centred care was recorded in 1972 (Yauger, 1972). Recall that older health-care professionals had more positive practices of family-centred care. Given the earlier findings of such researchers as

Dunn (1979) who found that older nurses had less positive attitudes toward family-centred care, these new findings suggest that positive change has occurred. The younger health-care professionals observed in Dunn's study who had more positive attitudes toward family-centred care would now be in the age group in this study that scored high on the practice of family-centred care.

Further, recalling that staff had more negative perceptions of family-centred care, this finding suggests that perhaps nonstaff had conversely more positive perceptions of family-centred care. Insufficient numbers of nonstaff were captured in this study to elaborate with any certainty (18%); however, it may be assumed that health-care professionals in nonstaff (i.e management, administration and education) positions had more seniority in terms of age and the corresponding years of experience. These years of experience may have also placed them into the cohort which was first exposed to family-centred care in the 1970's. These results provide evidence to indicate that positive strides have been made by health-care professionals since the 1970's.

The Dilemma of Helping

Dunst et al. (1988a) describe the "dilemma of helping which must be acknowledged by proponents of family-centred care" (p. 71). The dilemma of helping describes the disparity between the helping models typically employed by health-care professionals. It has been suggested that the elements of family-centred care are based upon principles which are designed to promote greater family self-determination, decision-making, capabilities, control and self-efficacy. Collectively, these attributes are said to reflect a sense of empowerment or an enablement model of helping (Dunst et al., 1988a; Dunst, Trivette & Deal, 1988b). In contrast, the medical model of helping directs health-care professionals to assume the roles of evaluator and controller of treatment interventions that result in child and parental dependence upon health-care providers (Dunst et al., 1988a). Merton, Merton and Barber (1983) as cited in Dunst et al. (1988a) indicate that most health-care professionals have been socialized to believe that only they are capable of helping their clients. To suggest otherwise becomes a threat to health-care professionals' sense of competence. When this position is embraced by health-care professionals it is in direct conflict with the conditions necessary for more active involvement of parents in the care of their health-impaired children (Nelkin, 1987; Shelton et al., 1987).

The qualitative component of this study provided

examples to illustrate the dilemma of helping. Subjects stated that they become child-centred when the child's well being is at stake, families are absent or dysfunctional and when the child is older. Subjects also report that sometimes parents should not be present as in cases of suspected child abuse or during painful procedures. Some subjects believed that the child's needs are always considered first. Whether or not the child-centred instances are appropriate is not at issue. In these examples, health-care professionals do not share the special child care responsibilities with families, thus avoiding any challenge to their expertise.

Practice

The dilemma of helping provides an explanation for the discrepancy between perceptions and practice of family-centred care found in this study and described by others (Blumenstein, 1986; Bruce, 1992; Odle, 1988; Porter, 1979). Support for this explanation is obtained by the lower perception scores of physicians and subjects with only professional specialties or post-secondary education and the higher scores of bachelor's educated health-care professionals. These findings will be related to the dilemma of helping which occurs when conflict arises between the medical and enablement models of helping.

Physicians clearly follow a medical model of helping and subjects who reported professional specialties as their highest level of education were predominately physicians. The influence of the medical model of helping may have contributed to the lower perception scores of these groups.

All but one of the subjects who reported post-secondary education as their highest level of education were nurses. Post-secondary educated nurses are normally trained to function in the acute care setting where the medical model predominates. Again, the influence of the medical model of helping may have contributed to post-secondary educated health-care professionals' lower perception scores.

Nurses also made up the largest proportion of bachelor's educated health-care professionals. Bachelor's educated nurses are prepared to function in a wider capacity not limited to the medical model. The finding that bachelor's education positively contributed to perceptions of family-centred care is consistent with being able to utilize an enablement model of helping like family-centred care.

These conclusions suggest a need for continuing education such as inservice education and workshops for

health-care professionals faced with the dilemma of helping. Content on the principles and practice of family-centred care would be helpful to all health-care professionals. An increased amount of interdisciplinary collaboration and coordination could also help to rectify and prevent the dilemma from affecting families and staff. Further, policies and guidelines for the implementation of family-centred care would be appropriate to help prevent and resolve the dilemma of helping. The ACH is committed to a philosophy of family-centred care (see Appendix C); however, the philosophy is not operationalized. Operationalization of the concept and guidelines for practice could enhance the practice of family-centred care. As suggested by responses to the qualitative component of the study, the lack of family-centred care practice guidelines for staff may reflect a need for increased administrative support of family-centred care policies.

The qualitative findings also suggested that the practice of family-centred care was largely influenced by financial cutbacks and provincial politics which resulted in layoffs, bumping, inexperienced staff and insufficient time with clients. As a result, health-care professionals may need to become more active in their advocating role for families with children with special health-care needs. Health-care professionals may need to lobby the government and educate health-care consumers more actively in order to ensure that the health-care environment is one that supports the practice of family-centred care activities.

Education

Education was discussed briefly above in the recommendation of continuing education for health-care professionals. Dunst et al. (1988a) suggest that the education of health-care professionals plays an important role in determining the helping model that professionals use in practice. Others have suggested that there is not enough family-centred content in educational programs for health-care professionals (Bailey, Simeonsson, Yoder & Huntington, 1990; Cochrane, Farley, & Wilhelm, 1990). Still, health-care professionals may not have the skills necessary to practice family-centred care such as communication and conflict management skills (Brown & Ritchie, 1989 & 1990). In support of these findings, some subjects who responded to the qualitative component of the questionnaire suggested improving educational programs for health-care professionals. Formal educational programs for health-care professionals should be examined to evaluate the theoretical and practical content of family-centred care. Teaching and clinical experiences should emphasize the practice of family-centred care and the effective integration of family-

centred care with other helping models such as the medical model. In particular, given the proportionally larger numbers of nurses compared to the numbers of other health-care professionals functioning in the health-care system and the relatively low perception scores of post-secondary educated nurses, post-secondary nursing education programs should be examined with the intent of improving and better integrating family-centred care content into curricula.

Research

Results from this research suggest a need for more research in the ways that health-care professionals successfully integrate the medical and enablement models of helping. Dunst et al. (1988a) suggest that "with the exception of immediately life-threatening conditions...the use of the enablement model of helping will increase the likelihood of family-centred care for children with special health care needs becoming a reality" (p. 79). This assertion appears to support the views of many respondents who described the emergency and life threatening conditions in which subjects became child-centred in practice. Frequently, these subjects reported becoming family-centred immediately after the crisis. Realistic research and discussion of the integration of the helping models in practice may diffuse the dilemma and associated negative feelings such as guilt and confusion associated with adhering to either the medical or family-centred care models.

The practice of family-centred care in the acute care setting could also be compared with the practice of family-centred care in the community or outpatient settings, where it is assumed the medical model does not predominate. If a large difference is found to exist between the practice of family-centred care activities in the hospital and community settings, this would provide support for the theory that the dilemma of helping explains health-care professionals' inability to practice family-centred care. It would also stress the need to closely examine how the helping models can be better integrated in the acute care setting.

Research is also suggested to test the effect of education on the perceptions and practices of family-centred care. The education intervention could also be tested to determine its effect on the integration of the helping models in practice. A pre-test post-test design might be effective to determine the influence of education. Further, the educational intervention could encourage the use of interdisciplinary collaboration and likewise test the assumption that such collaboration fosters the perceptions and practice of effective family-centred care. Subjects

should be encouraged to operationalize conceptually family-centred care through interactive teaching methods such as role playing and brainstorming. The effect of widespread administrative support on perceptions and practices of family-centred care could also be examined by a pre-test post-test design. To demonstrate the optimal practice of family-centred care, families should be included in these studies.

Conclusions

In addition to the normally expected discrepancy between measures of ideal and real situations, the discrepancy between perceptions and practice of family-centred care was significant and large. The discrepancy between perceptions and practices of family-centred care may be explained by the dilemma of helping, education and knowledge, experience, staff position, financial and time constraints, communication, and the organizational setting. The effect of the cohort suggests that positive strides have been made by health-care professionals in their understanding of family-centred care. Further exploration of issues that contribute to or detract from the ability of health-care professionals to practice family-centred care is recommended. A realistic and improved understanding of the integration of the helping model of family-centred care and the medical model is encouraged in practice, education and research. This understanding will not only improve practice but work towards the achievement of excellence in the care of families and children with special health-care needs.

References

Algren, C. (1985). Role perception of mothers who have hospitalized children. Children's Health Care, 14(1), 6-9.

Allen, M. & Yen, W. (1979). Introduction to measurement theory. Monterey, California: Brooks/Cole Publishing Company.

Arrango, P. (1990). A parent's perspective. "Family-centred care": Making it a reality. Children's Health Care, 19(1), 57-62.

Ayer, A. (1978). Is partnership with parents really possible? American Journal of Maternal child Nursing, 3(2), 107-109.

Bailey, D., Buysse, V., Edmondson, R. & Smith, T. (1992). Creating family-centred services in early intervention: Perceptions of professionals in four states. Exceptional Children, 58(4), 298-309.

Bailey, D., Buysse, V., Smith, T. & Elam, J. (1992). The effects and perceptions of family involvement in program decisions about family-centred practices. Evaluation and Program Planning, 15(1), 23-32.

Bailey, D., McWilliam, P. & Winton, P. (1992). Building family-centred practices in early intervention: A team-based model for change. Infants and Young Children, 5(1), 73-82.

Bailey, D., Palsha, S. & Simeonsson, R. (1991). Professional skills, concerns, and perceived importance of work with families in early intervention. Exceptional Children, 58(2), 156-165.

Bailey, D., Simeonsson, R., Yoder, D. & Huntington, G. (1990). Preparing professionals to serve infants and toddlers with handicaps and their families: An integrative analysis across eight disciplines. Exceptional Children, 57(1), 26-35.

Berman, H. (1991). Nurses' beliefs about family involvement in a children's hospital. Issues in Comprehensive Pediatric Nursing, 14(3), 141-153.

Blumenstein, H. (1986). Maintaining a family focus: Underlying issue and challenges. Clinical Social Work Journal, 14(3), 238-249.

Bowlby, J. (1951). Maternal care and mental health. Geneva: World Health Organization.

Bowlby, J. (1953). Some pathological processes set in train by early mother-child separation. Journal of Mental Science, 99(415), 265-272.

Bowlby, J. (1957). Child care and the growth of love (3rd Ed.). Pelican, London.

Bowlby, J. (1960). Separation anxiety. The International Journal of Psycho-Analysis, 41, 89-113.

Brewis, E. (1986). Parental perogatives. Nursing Times, 24, 34-35.

Brain, D. & Maclay, I. (1968). A controlled study of mothers and children in hospital. British Medical Journal, 1(5587), 278-280.

Brink, P. & Wood, M. (1989). Advanced design in nursing research. Newbury Park, California: Sage.

Brown, J. & Ritchie, J. (1989). Nurses' perceptions of their relationships with parents. Maternal-Child Nursing Journal, 18(2), 79-96.

Brown, J. & Ritchie, J. (1990). Nurses' perceptions of parent and nurse roles in caring for hospitalized children. Children's Health Care, 19(1), 28-36.

Bruce, B. (1992). Nurses' perceptions and practices of family centred care. Unpublished master's thesis, Dalhousie University, Halifax.

Bruce, B. (1993). Health care professionals' perceptions and practices of family-centred care: Canadian Nurses' Foundation grant proposal. (Available from Beth Bruce, Research Associate, Nursing, IWK Hospital for Children, 5850 University Avenue, Halifax, N.S., B3J 3G9.

Burrows, I. (1972). Pediatric diabetes: A family-centred day care program. Canadian Hospital, 49(5), 47-53.

Caldwell, B. & Lockhart, L. (1981). A care-by-parent unit: Its planning, implementation and patient satisfaction. Children's Health Care, 10(1), 4-7.

Callery, P. & Smith, L. (1991). A study of role negotiation between nurses and the parents of hospitalized children. Journal of Advanced Nursing, 16(7), 772-781.

Caro, P. & Derevensky, J. (1991). Family-focused intervention model: Implementation and research findings. Topics in Early Childhood Special Education, 11(3), 66-80.

Cleary, J. Gray, O., Hall, D., Rowlandson, P., Sainsbury, C. & Davies, M. (1986). Parental involvement in the lives of children in hospital. Archives of Disease in Childhood, 61(8), 779-787.

Cochrane, C., Farley, B. & Wilhelm, I. (1990). Preparation of physical therapists to work with handicapped infants and their families: Current status and training needs. Physical Therapy, 70(6), 372-380.

Craig, J. & McKay, E. (1958). Working of a mother and baby unit. British Medical Journal, 1, 275-277.

Dunkel, J. & Eisendrath, S. (1983). Families in the intensive care unit: Their effect on staff. Heart and Lung, 12(3), 258-261.

Dunn, B. (1979). Who's resisting parent participation? Pediatric Nursing, 5, 54.

Dunst, C., Johanson, C., Trivette, C. & Hamby, D. (1991). Family-oriented early intervention policies and practices: Family-centred or not? Exceptional Children, 58(2), 115-126.

Dunst, C., Trivette, C., Davis, M. & Cornwell, J. (1988a). Enabling and empowering families of children with health impairments. Children's Health Care, 17(2), 71-81.

Dunst, C., Trivette, C., Deal, A. (1988b). Enabling and empowering families: Principles and guidelines for practice. Cambridge, MA: Brookline.

Eldar, R. & Eldar, E. (1984). A place for the family in hospital life. International Nursing Review, 31(2), 40-42.

Evans, R. & Robinson, G. (1983). An economic study of cost savings on a care-by-parent ward. Medical Care, 21(8), 768-782.

Ferketich, S. & Muller, M. (1990). Factor analysis revisited. Nursing Research, 39(1), 59-62.

Fond, K. (1972). Dealing with death and dying through family-centred care. Nursing Clinics of North America, 7(1), 53-64.

Frankl, S., Shiere, F., & Fogels, H. (1962). Should the parent remain with the child in the dental operatory? Journal of Dentistry for Children, 29(2), 150-163.

George, A. & Hancock, J. (1993). Reducing pediatric burn pain with parent participation. Journal of Burn Care & Rehabilitation, 14(1), 104-107.

Gill, K. (1987a). Nurses' attitudes toward parent participation: Personal and professional characteristics. Children's Health Care, 15(3), 149-151.

Gill, K. (1987b). Parent participation with a family health focus: Nurses' attitudes. Pediatric Nursing, 13(2), 94-96.

Gillette, Y., Hansen, N., Robinson, J., Kirkpatrick, K. & Grywalski, R. (1990). Hospital-based case management for medically fragile infants: Results of a randomized trial. Patient Education and Counselling, 17(1), 59-70.

Goodley, S. (1985). A family affair. Nursing Mirror, 161(9), 17-19.

Green, M. & Green, J. (1977). The parent care pavilion. Children Today, 6(5), 5-8, 36.

Gunn, T. & Nightingale, A. (1989). Quality of outcome and cost in an obstetric and neonatal service. New Zealand Medical Journal, 102(864), 136-140.

Harris, J. (1990). Family-centred maternity care: The nurse administrator's role. Canadian Journal of Nursing Administration, 3(1), 16-18.

Hayes, V. & Knox, J. (1984). The experience of stress in parents of children hospitalized with long-term disabilities. Journal of Advanced Nursing Research, 9(4), 333-341.

Humphry, R., Gonzalez, S. & Taylor, E. (1993). Family involvement in practice: Issues and attitudes. The American Journal of Occupational Therapy, 47(7), 587-593.

Hutchins, V. & McPherson, M. (1991). National agenda for children with special health needs. American Psychologist, 46(2), 141-143.

Illingworth, R. & Holt, K. (1955). Children in hospital: Some observations on their reactions with special reference to daily visiting. Lancet, 269(6903), 1257-1262.

Izaak Walton Killam Hospital for Children (1992, May). Family-centred care position paper. (Available from Izaak Walton Killam Hospital for Children Family-Centred Care Committee, Halifax, Nova Scotia).

Jackson, P., Bradham, R., & Burwell, H. (1978). Child care in the hospital - a parent/staff partnership. MCN, 3(2), 104-107.

Jessner, L., Blom, G. & Waldfogel, S. (1952). Emotional implications of tonsillectomy and adenoidectomy on children. The Psychoanalytic Study of the Child, 7, 126-169.

Johnson, B., Jeppson, E., & Redburn, L. (1992). Caring for children and families: Guidelines for Hospitals. Betheseda, Maryland: Association for the Care of Children's Health.

Kay, B. (1966). Outpatient anaesthesia, especially for children. Acta Anaesthesiologica Scandinavica. suppl., 25, 421-425.

Kelly, P. (1993). Organizing health care for families affected by HIV. British Journal of Nursing, 2(16), 810-812.

Knafl, K., Cavallari, K., & Dixon, D. (1988). Pediatric hospitalization: Family and nurse perspectives. Boston: Scott Foresman and Company.

Koop, C. (1987). Surgeon General's report: Children with special health care needs. Commitment to family-centred coordinated care for children with special health care needs. Rockville, Maryland: U.S. Department of Health & Human Services.

Korteland, C. & Cornwell, J. (1991). Evaluating family-centred programs in neonatal intensive care. Children's Health Care, 20(1), 56-61.

Latter, S., Clark, J., Wilson-Barnett, J. & Maben, J. (1992). Health education in nursing: perceptions of practice in acute settings. Journal of Advanced Nursing, 17(2), 164-172.

Leavitt, M. (1984). Nursing and family-focused care. Nursing Clinics of North America, 19(1), 83-87.

Lewis, M., Hatton, C., Salas, I., Leake, B. & Chiofalo, N. (1991). Impact of the children's epilepsy program on parents. Epilepsia, 32(3), 365-374.

Lewis, M., Salas, I., de la Sota, A., Chiofalo, N. & Leake, B. (1990). Randomized trial of a program to enhance the competencies of children with epilepsy. Epilepsia, 31(1), 101-109.

Luciano, K. (1972a). Components of planned family-centred care. Nursing Clinics of North America, 7(1), 41-51.

Luciano, K. (1972b). Staff development: toward the implementation of family-centred care. Nursing Clinics of North America, 7(1), 75-82.

MacCarthy, D. (1957). Mothers in a children's ward. Public Health, 71(7), 264-266.

Mahaffy, P. (1965). The effects of hospitalization on children admitted for tonsillectomy and adenoidectomy. Nursing Research, 14(1), 12-19.

Mahoney, G. & O'Sullivan, P. (1990). Early intervention practices with families of children with handicaps. Mental Retardation, 28(5), 169-176.

Mahoney, G., O'Sullivan, P. & Dennebaum, J. (1990). A national study of mothers' perceptions of family-focused early intervention. Journal of Early Intervention, 14(2), 133-147.

Marriott, S. (1990). Parent power. Nursing Times, 86(34), 68.

Marvel, M. & Morphew, P. (1993). Levels of family involvement by resident and attending physicians. Family Medicine, 25(1), 26-30.

Mason, E. (1978). Hospital and family cooperating to reduce psychological trauma. Community Mental Health Journal, 14(2), 153-159.

McBride, S., Brotherson, M., Joanning, H., Whiddon, D. & Demmitt, A. (1993). Implementation of family-centred services: Perceptions of families and professionals. Journal of Early Intervention, 17(4), 414-430.

McElnea, L. (1971). Where resident parents are welcome. Nursing Times, 67, 1331-1333.

McKenzie, S., Kurtianyk, O., Kidd, M., Knowles, D. & Lipman, H. (1993). Advice to a Moscow children's hospital. British Medical Journal, 306(6882), 914-916.

Meadow, S. (1969). The captive mother. Archives of Disease in Childhood, 44(235), 362-367.

Menzies, R., Parkin, J. & Hey, E. (1985). Prognosis for babies with meningomyelocele and high lumbar paraplegia at birth. Lancet, 2(8462), 993-997.

Merton, V., Merton, R. & Barber, E. (1983). Client ambivalence in professional relationships: The problem of seeking help from strangers. In B. DePaulo, A. Nadler, & J. Fisher (Eds.), New directions in helping: Vol. 2. Help-seeking and -receiving. New York: Academic.

Munro, B. & Page E. (1993). Statistical methods for health care research (2nd Ed.). Philadephia: J. B. Lippincott.

National Association for the Welfare of Children in Hospital (NAWCH) (1988). Parents Staying Overnight in Hospital With Their Children. London, England: NAWCH.

Nelkin, V. (1987). Family-centred health care for medically fragile children: Principles and practice. Washington, DC: Georgetown University, National Center for Networking Community Based Services.

Nethercott, S. (1993). A concept for all the family. Family centred care: A concept analysis. Professional Nurse, 8(12), 794-797.

Nissen, C. (1969). The case for parent-child nursing. RN, 32, 80-89.

Odle, K. (1988). Partnership for family-centred care: Reality or fantasy? Children's Health Care, 17(2), 85-86.

Ogilvie, L. (1990). Hospitalization of children for surgery: The parents' view. Children's Health Care, 19(1), 49-56.

Palmer, S. (1993). Care of sick children by parents: a meaningful role. Journal of Advanced Nursing, 18(2), 185-191.

Palys, T. (1992). Research decisions: Quantitative and qualitative perspectives. Toronto: Harcourt Brace Jovanovich.

Park, C. (1991). Parenting the hospitalized child. Unpublished doctoral dissertation, University of Alberta, Edmonton.

Pass, M. & Pass, c. (1987). Anticipatory guidance for parents of hospitalized children. Journal of Pediatric Nursing, 2(4), 250-258.

Patterson, P. (1979). Chospitology: The art and science of rendering hospitalization as benign an experience as possible for a child. Dimensions in Health Service, 56(5), 12-15.

Pickerill, C. & Pickerill, H. (1954). Elimination of hospital cross-infection in children: Nursing by the mother. Lancet, 266(6809), 425-429.

Pike, S. (1989). Family participation in the care of central venous lines. Nursing, 3(38), 22-25.

Plank, E., Caughey, P., Lipson, M. (1959). A general hospital child care program to counteract hospitalism. American Journal of Orthopsychiatry, 29(1), 94-101.

Platt, H. (1959). The welfare of children in hospital, report of the Committee. London, England: Ministry of Health, Central Services Council, HMSO.

Polit, D. & Hungler, B. (1983). Nursing research: Principles and Methods. (2nd ed.). Toronto: J.B. Lippincott.

Porter, L. (1974). Porter Family-Centred Child Care Scale (FCCS). University Park, Pennsylvania State University (unpublished).

Porter, L. (1979). Health care workers' role conceptions and orientation to family-centred care. Nursing Research, 28(6), 330-337.

Prugh, D. Staub, E., Sands, H., Kirschbaum, R. & Lenihan, E. (1953). A study of the emotional reactions of children and families to hospitalization and illness. American Journal of Orthopsychiatry, 23(1), 70-106.

Ramey, C., Bryant, D., Wasik, B., Sparling, J., Fendt, K. & LaVange, L. (1992). Infant health and development program for low birth weight, premature infants: Program elements, family participation, and child intelligence. Pediatrics, 89(3), 454-465.

Robbins, M. (1987). The role of the nurse. Nursing, 3(24), 905-907.

Robbins, M. (1991). Sharing the care...family-centred care in her pediatric ward. Nursing times, 87(8), 36-38.

Roberts, R. & Magrab, P. (1991). Psychologists' role in a family-centred approach to practice, training, and research with young children. American Psychologist, 46(2), 144-148.

Robertson, J. (1953). Some responses of young children to losses of maternal care. Nursing Times, 49, 382-386.

Robertson, J. & Bowlby, J. (1952). Responses of young children to separation from their mothers. Courr. Cent. International d'Enfants. 2, 131-142.

Robinson, C. (1985). Double blind: A dilemma for parents of chronically ill children. Pediatric Nursing, 11(2), 112-115.

Robinson, C. (1987). Roadblocks to family-centred care when a chronically ill child is hospitalized. MCN Journal, 16(3), 181-193.

Robinson, G., Shah, C., Argue, C., Kinnis, C., & Israels, S. (1969). A study of the need for alternative types of health care for children in hospitals. Pediatrics, 43(5), 866-878.

Rosenbaum, P., King, S., Cadman, D. (1992). Measuring processes of caregiving to physically disabled children and their families. I: Identifying relevant components of care. Developmental Medicine and Child Neurology, 34(2), 103-14.

Rushton, C. (1990). Family-centred care in the critical care setting: Myth or reality? Children's Health Care, 19(2), 68-78.

Sainsbury, C., Gray, O., Cleary, J., Davies, M., & Rowlandson, P. (1986). Care by parents of their children in hospital. Archives of Disease in Childhood, 61(6), 612-615.

Saylor, C., Elksnin, N., Farah, B. & Pope, J. (1990). Depends of who you ask: What maximizes participation of families in early intervention programs. Journal of Pediatric Psychology, 15(4), 557-569.

Schaffer, H. & Callendar, W. (1959). Psychologic effects of hospitalization in infancy. Pediatrics, 24, 528-539.

Schulman, J., Foley, J., Vernon, D., Allan, D. (1967). A study of the effect of the mother's presence during anaesthesia induction. Pediatrics, 39(1), 111-114.

Shea-McAleavey, C. & Janusz, B. (1991). Sibling visitation - a plan for change. Dimensions of Critical Care Nursing, 10(4), 218-222.

Shelton, T., Jeppson, E., & Johnson, B. (1987). Family-centred care for children with special health care needs. Washington, D.C.: Association for the Care of Children's Health.

Shelton, T., Jeppson, E., & Johnson, B. (1989). Family-centred care for children with special health needs. (2nd ed.). Washington, D.C.: Association for the Care of Children's Health.

Siedl, F. (1969). Paediatric nursing personnel and parent participation: A study in attitudes. Nursing Research, 18(1), 40-44.

Siegel, R. (1982). A family-centred program of neonatal intensive care. Health and Social Work, 7(1), 50-58.

Skipper, J. & Leonard, R. (1968). Children, stress, and hospitalization: A field experiment. Journal of Health and Social Behaviour, 9, 275-287.

Spence, J. (1947). The care of children in hospital. British Medical Journal, 1(4490), 125-130.

Spence, J. (1951). The doctor, the nurse, and the sick child. The American Journal of Nursing, 51(1), 14-16.

Spitz, R. (1945). Hospitalism: An inquiry into the genesis of psychiatric conditions in early childhood. The Psychoanalytic Study of the Child, 1, 53-74.

Styba, J., Elaschuk, S., Jesse, B. & Cote, J. (1992, October). An evaluation of a parent satisfaction survey of patients admitted to a care by parent unit. Paper presented at the conference on the Changing World of Pediatric Health Care, University of Alberta, Edmonton, Alberta.

Thomas, R. (1987). Family adaptation to a child with a chronic condition. In M. Rose & R. Thomas (Eds.). Children with chronic conditions: Nursing in a family and community context. (p. 29-54). New York: Grune & Stratton.

Thompson, J. (1985). Family-centred care. Nursing Mirror, 160(7), 25-28.

Thornes, R. (1983). Parental access and family facilities in children's wards in England. British Medical Journal, 287(6386), 190-192.

Thornes, R. (1985). Parent participation. Nursing Mirror, 160(13), 20-22.

van der Schyff, G. (1979). The role of parents during their child's hospitalisation. The Australian Nurses' Journal, 11(8), 57-58, 61.

Vaughn, G. (1957). Children in hospital. Lancet, 272(6979), 1117-1120.

Verghese, A. (1988). Family participation in mental health care - the Vellore experiment. Indian Journal of Psychiatry, 30(2), 117-121.

Vermillion, B., Ballantine, T., & Grosfield, J. (1979). The effective use of the parent care unit for infants on the surgical service. Journal of Pediatric Surgery, 14(3), 321-324.

Webb, N., Hull, D. & Madeley, R. (1985). Care by parents in hospital. British Medical Journal, 291(7), 176-177.

Weinstein, A., Faust, D., McKee, L., Padman, R. (1992). Outcome of short-term hospitalization for children with severe asthma. Journal of Allergy and Clinical Immunology, 90(1), 66-75.

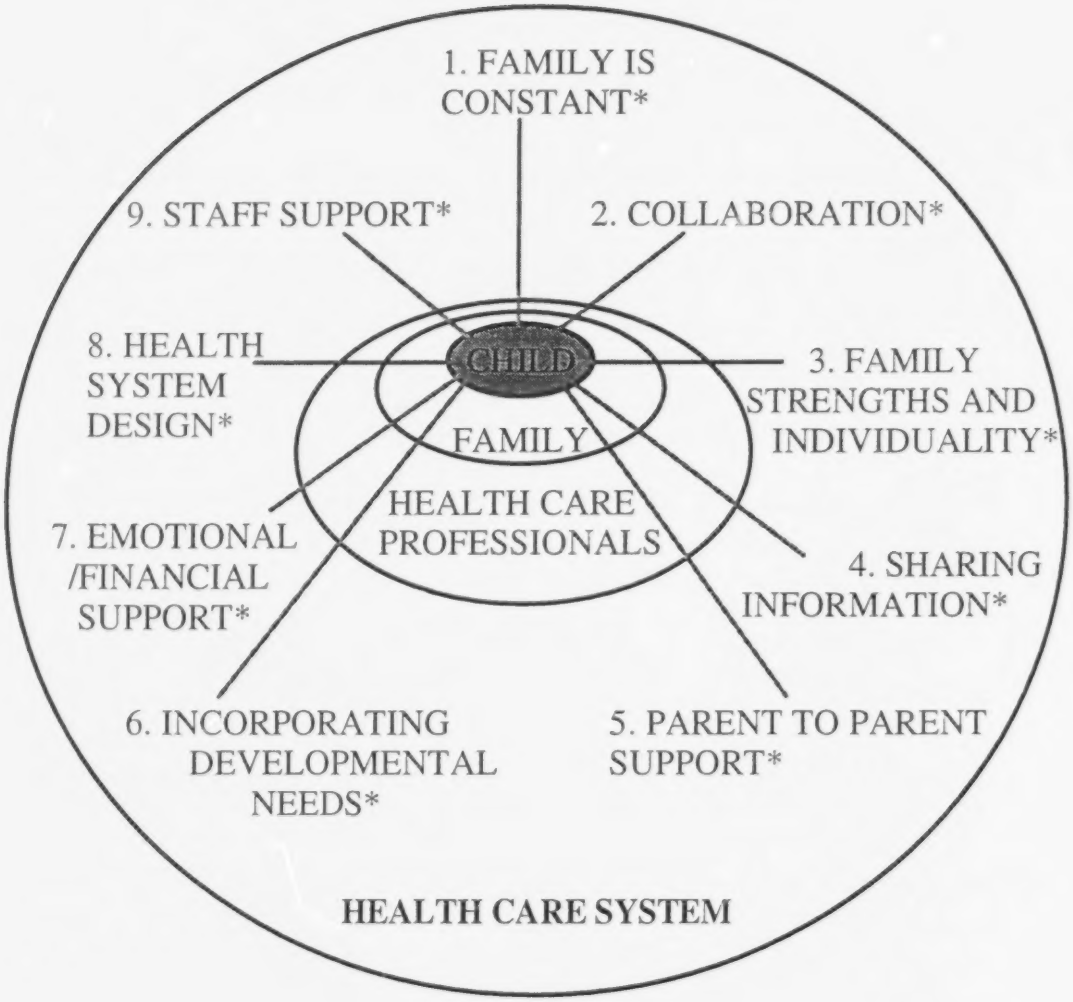
Wolfer, J. & Visintainer, M. (1975). Pediatric surgical patients' and parents' stress responses and adjustment. Nursing Research, 24(4), 244-255.

Woods, N. & Catanzaro, M. (1988). Nursing research: Theory and practice. Toronto: C.V. Mosby.

Yauger, R. (1972). Does family-centred care make a difference? Nursing Outlook, 20(5), 320-323.

Young, J. (1992). Changing attitudes towards families of hospitalized children from 1935 to 1975: A case study. Journal of Advanced Nursing, 17(2), 1422-1429.

Appendix A



FAMILY-CENTERED CARE CONCEPTUAL FRAMEWORK

* The nine elements of family-centered care as defined by the ACCH and the IWK Family-Centered Care Committee

University of Alberta
Edmonton

Pediatric Health Care Professionals' Perceptions and Practices of Family-Centred Care

NICOLE L. LETOURNEAU, RN, BN

A STUDY CONDUCTED IN PARTIAL FULFILMENT OF THE REQUIREMENTS FOR THE M.N. DEGREE.

Faculty of Nursing
University of Alberta
Edmonton, Alberta
T6G 2G3

Family-Centred Care Questionnaire Revised

© Copyright by Beth S. Bruce 1993

The following questions refer to **your** beliefs about what family-centred care is or is not. We are interested in knowing how well these items represent your **practice and perceptions** of family-centred care.

DIRECTIONS

Everyday Work

Carefully think about each item with respect to the extent to which you **include this aspect of care in your everyday work**. Circle the appropriate letters that indicate your response under the **Everyday Work** column.

Necessary

Carefully think about each item with respect to whether you believe that this aspect of care is **necessary for family-centred care to be provided**. Circle the appropriate letters that indicate your response under the **Necessary** column.

Example:

Strongly Agree / Agree / Neutral / Disagree / Strongly Disagree / Not Applicable
SA A N D SD NA

	Everyday Work						Necessary				
Staff encourage families to attend patient care conferences.	SA	A	N	D	SD	NA	SA	A	N	D	SD

NOTE: Not Applicable should be chosen **ONLY** if the item cannot exist in your everyday work environment.

DEFINITIONS

Staff refers to **you in your role** as a health-care professional being surveyed in this study: child life specialists, nurses, nutritionists, occupational therapists, pharmacists, physicians, physiotherapists, psychologists, respiratory therapists, social workers, and speech & language pathologists/audiologists.

Family refers to parents, guardians, grandparents, and siblings, and any family relative or friend who is significantly involved with the child's everyday life or care.

Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree	Not Applicable
SA	A	N	D	SD	NA

Staff refers to **you in your role** as a health-care professional being surveyed in this study: child life specialists, nurses, nutritionists, occupational therapists, pharmacists, physicians, physiotherapists, psychologists, respiratory therapists, social workers, and speech & language pathologists/audiologists.

Family refers to parents, guardians, grandparents, and siblings, and any family relative or friend who is significantly involved with the child's everyday life or care.

	Everyday Work	Necessary
1. Staff encourage parents and siblings to come and go any time that meets the family's needs.	SA A N D SD NA	SA A N D SD
2. Staff work with families to determine the level of participation in direct care and decision-making that suits the family's needs best.	SA A N D SD NA	SA A N D SD
3. The family is the key decision maker in the care of their child.	SA A N D SD NA	SA A N D SD
4. Staff determine the child's needs in consultation with the family and other health professionals.	SA A N D SD NA	SA A N D SD
5. Parents contribute to the development and review of hospital policies and practices.	SA A N D SD NA	SA A N D SD
6. Parents and siblings are involved in staff orientation and continuing education programs.	SA A N D SD NA	SA A N D SD
7. Educational programs and written material convey the sense that families are the key participants in care.	SA A N D SD NA	SA A N D SD
8. The admission process is used as an opportunity to begin involving the family as members in the health care team.	SA A N D SD NA	SA A N D SD

	Everyday Work	Necessary
9. Hospital facilities, policies, and procedures foster family choices for participation.	SA A N D SD NA	SA A N D SD
10. Interviews with families are conducted in a private location.	SA A N D SD NA	SA A N D SD
11. Explanations are presented to the family, using a variety of techniques depending on the individual needs and learning styles of the family.	SA A N D SD NA	SA A N D SD
12. Staff are aware of and take approaches that address the fact that families take time to develop trust.	SA A N D SD NA	SA A N D SD
13. Staff discuss with the child and family what helps them deal with events during hospitalization.	SA A N D SD NA	SA A N D SD
14. Staff assess the level of understanding and skills of the child and family before and after teaching	SA A N D SD NA	SA A N D SD
15. Staff promote preadmission programs which familiarize children and families with hospital staff, routines, and equipment prior to a scheduled admission.	SA A N D SD NA	SA A N D SD
16. After an emergency admission or unscheduled admission, there is an organized system for helping children and families understand and adjust to the health care experience.	SA A N D SD NA	SA A N D SD
17. Information is routinely communicated to help families understand each aspect of care that their child will experience such as anticipated sequence of events, reasons for change/treatment/procedure, ways to cope.	SA A N D SD NA	SA A N D SD

Strongly Agree / Agree / Neutral / Disagree / Strongly Disagree / Not Applicable

SA A N D SD NA

Staff refers to **you in your role** as a health-care professional being surveyed in this study: child life specialists, nurses, nutritionists, occupational therapists, pharmacists, physicians, physiotherapists, psychologists, respiratory therapists, social workers, and speech & language pathologists/audiologists.

Family refers to parents, guardians, grandparents, and siblings, and any family relative or friend who is significantly involved with the child's everyday life or care.

	Everyday Work	Necessary
18. Any family member significantly involved in the child's care is encouraged to discuss or chart information about the care of their child.	SA A N D SD NA	SA A N D SD
19. Staff coordinate the flow and sequence of information given to children and their families, ensuring that the child's information needs are a priority.	SA A N D SD NA	SA A N D SD
20. Staff encourage parents to discuss concerns with other parents with similar experiences informally or in formal parent groups.	SA A N D SD NA	SA A N D SD
21. Staff provide programs and support for parents, siblings, and members of the extended family to assist families in managing needs.	SA A N D SD NA	SA A N D SD
22. Staff assess the needs and concerns of siblings.	SA A N D SD NA	SA A N D SD
23. There is a designated comfortable area for parents to gather.	SA A N D SD NA	SA A N D SD
24. Staff help children and family stay in touch with their family and friends.	SA A N D SD NA	SA A N D SD

	Everyday Work	Necessary
25. Direct care managers have an adequate knowledge in child development to support hospital staff in the practice of family-centred care.	SA A N D SD NA	SA A N D SD
26. Hospital brochures accurately describe the health care experience for children and their families.	SA A N D SD NA	SA A N D SD
27. Staff maintain familiar routines for each child and family.	SA A N D SD NA	SA A N D SD
28. Staff assess the child's interaction with staff, peers, and family.	SA A N D SD NA	SA A N D SD
29. When possible, the same staff are assigned to care for the child and family.	SA A N D SD NA	SA A N D SD
30. Information and support are provided to help families understand the illness process and the impact on the child and family, choices and risks, services, and roles of various health professionals.	SA A N D SD NA	SA A N D SD
31. Staff recognize the financial strain on families and assist them in obtaining help.	SA A N D SD NA	SA A N D SD
32. During procedures, a staff member is designated to explain to the child and family exactly what is happening.	SA A N D SD NA	SA A N D SD
33. Nonurgent outpatient services are available daily and in the evening hours.	SA A N D SD NA	SA A N D SD
34. All written material for families is available in French/English versions.	SA A N D SD NA	SA A N D SD

Strongly Agree / Agree / Neutral / Disagree / Strongly Disagree / Not Applicable

SA A N D SD NA

Staff refers to **you in your role** as a health-care professional being surveyed in this study: child life specialists, nurses, nutritionists, occupational therapists, pharmacists, physicians, physiotherapists, psychologists, respiratory therapists, social workers, and speech & language pathologists/audiologists.

Family refers to parents, guardians, grandparents, and siblings, and any family relative or friend who is significantly involved with the child's everyday life or care.

	Everyday Work	Necessary
35. A written summary of relevant information about the child is available in the primary official language of the family.	SA A N D SD NA	SA A N D SD
36. The physical layout of the unit is designed to meet the developmental and psychosocial needs of the child and family.	SA A N D SD NA	SA A N D SD
37. Resources exist to help provide families with the appropriate support that they need at varying times.	SA A N D SD NA	SA A N D SD
38. Parent evaluations are considered reliable souraces of information about how well the hospital meets their needs.	SA A N D SD NA	SA A N D SD
39. Staffing patterns are planned according to the develpmental and psychosocial needs of children.	SA A N D SD NA	SA A N D SD
40. There are guidelines to assist staff in providing care during painful procedures such as: teaching children ways to cope with pain and post-procedural debriefing of the child.	SA A N D SD NA	SA A N D SD

	Everyday Work	Necessary
41. Job descriptions and performance appraisal systems incorporate expectations of family-centred care such as: knowledge of family dynamics and skills in collaboration, problem solving and interventions that address families' needs.	SA A N D SD NA	SA A N D SD
42. Continuing education programs provide opportunities for staff to learn to deal effectively with families.	SA A N D SD NA	SA A N D SD
43. The hospital recognizes and rewards special knowledge and skills that are needed to care for children and families.	SA A N D SD NA	SA A N D SD
44. Staff are encouraged to identify, plan and evaluate new programs, policies and procedures to improve the quality of patient and family care.	SA A N D SD NA	SA A N D SD
45. Staff are able to express confidentially to those responsible for assuring quality care, their concerns related to those demands of providing care for their children and families.	SA A N D SD NA	SA A N D SD

46. Do you think there is a large difference between your everyday work and what you think is necessary to practice family-centred care? Is so, why? If not, why?

47. If there are instances in which you become child-centred instead of family-centred in your approach to care, please describe.

48. Please list any suggestions of what is needed to enhance family-centred care.

49. Please write any additional comments below.

Your anonymity will be maintained throughout this study and in the reporting of study findings. In response to the questions on this page, please indicate if you:

- ❑ do not want to be quoted anonymously.
- ❑ do not mind being quoted anonymously.

Demographic Sheet

Please complete the following general information.

1. Age (circle) Less than 31 31 - 40 41 - 50 51 - 60 over 60

2. Years of experience at

   Alberta Children's Hospital _____

   Other Pediatric Setting _____

3. Clinical Position

   Administrative Position _____

   Manager _____

   Education _____

   Staff _____

   Other (please specify) _____

4. Highest level of education (check as many as apply)

   Post Secondary (eg. College) _____

   Bachelor's Degree _____

   Professional Specialty (eg. MD) _____

   Master's Degree _____

   Doctoral Degree _____

   Specialty Certificate (eg. NICU, NCAST; please specify) _____

   Other (please specify) _____

Continued on Page 10

Demographic Sheet (continued)

5. Health Profession

Child Life Specialist	_____
Nurse	_____
Nutritionist	_____
Occupational Therapist	_____
Pharmacist	_____
Physician	_____
Physiotherapist	_____
Psychologist	_____
Respiratory Therapist	_____
Social Worker	_____
Speech/Language Pathologist/Audiologist	_____
Other (please specify)	_____

6. Are you a parent? (circle) YES NO

7. In which Department / Program / Unit do you work?

_____

THANK YOU FOR YOUR PARTICIPATION.

ALBERTA CHILDREN'S HOSPITAL
CHILD HEALTH CENTRE

Alberta Children's Provincial General Hospital

MISSION STATEMENT

We are a major centre of excellence in Canada for the care and treatment of children from birth to 18 years. We are a referral Child Health Centre dedicated to meeting complex pediatric health care needs through preventive, outpatient, outreach, emergency and inpatient programs. We are committed to excellence of service and to multidisciplinary, family-centred care with recognition of the physical, psychological and social needs of each child. We support regionalization and actively collaborate with universities, hospitals and other health care providers to optimize the pediatric resources available to the children of Alberta. We will continue our tradition of leadership in pediatric research, education, and innovative prevention, diagnosis and treatment of childhood diseases and handicapping conditions.

ROLE STATEMENT

The Alberta Children's Hospital is the regional pediatric health centre. With the support of the Alberta Children's Hospital Foundation and Research Centre, we provide quality programs and services in pediatric health care, research and education.

Pediatric Health Care: *Our priorities are in the provision of specialized and tertiary pediatric care, in both ambulatory and inpatient settings. Our programs require a medical, professional, technical or multidisciplinary approach to the specialized care of children and include primary, secondary, tertiary and trauma care.*

Pediatric Education: *Our Hospital has a primary affiliation with the University of Calgary for pediatric education in medicine, nursing and the allied health professions. We will continue our responsibility to educate and to promote the health of children in the community by providing a comprehensive range of pediatric health care information, advocacy and outreach services.*

Pediatric Research: *Our Research Centre, in collaboration with our Hospital and the University of Calgary, pursues international calibre research in specialized areas of pediatrics. We will maintain our research leadership throughout our organization to ensure the future health of our children and the children of the future.*

July 09, 1990

03-29-1994 09:39AM FROM PEDIATRICS TO 11613089149225S1 P.02

THE UNIVERSITY OF
CALGARY

Faculty of MEDICINE
Office of MEDICAL BIOETHICS

1994-03-22

Ms. Norah Greenley
Department of Nursing
Alberta Children's Hospital
Calgary, Alberta

Dear Ms. Greenley:

Re: Pediatric Health-Care Professionals' Perceptions and Practices of Family Centred Care

As a member of the Conjoint Medical Ethics Committee of the Faculty of Medicine, University of Calgary, and the Affiliated Teaching Institutions, I am writing to advise you that the above-noted study has been granted interim approval with respect to ethical considerations.

Please note that interim approval permits you to initiate your study but the latter must not deviate from the approved protocol, and you must also obtain approval from your appropriate administrative Head (Hospital or University).

Each subject enrolled in your study must be given a copy of the informed consent form to retain.

Your protocol will be submitted to the Conjoint Medical Ethics Committee for final review. Upon completion of the latter process, you will be advised of any relevant recommendations.

Yours sincerely,

E. D. Burgess, MD, FRCPC, FACP
Chair, Conjoint Medical Ethics
Committee

c.c. Research Committee,
Alberta Children's Hospital

3330 Hospital Drive N.W., Calgary, Alberta, Canada T2N 4N1
Telephone: (403) 220-7990 Fax: (403) 283-8524

Appendix E

THE UNIVERSITY OF CALGARY
Faculty of MEDICINE
Office of MEDICAL BIOETHICS

1994-04-19

Dr. N. Greenley
Department of Nursing
Alberta Children's Hospital
Calgary, Alberta.

Dear Dr. Greenley:

Re: Pediatric Health-Care Professionals' Perceptions and Practices of Family Centred Care

Student: Ms. Nicole L. Letourneau

Degree Program: MScN

The above-noted thesis proposal has been submitted for Committee review and found to be ethically acceptable.

Yours sincerely,

E Burgess

E.D. Burgess, MD, FRCPC, FACP
Chair,
Conjoint Medical Ethics Committee

c.c. Research Committee,
Alberta Children's Hospital
Ms. Nicole L. Letourneau

3330 Hospital Drive N.W., Calgary, Alberta, Canada T2N 4N1
Telephone: (403) 220-7990 Fax: (403) 283-8524

Appendix F: Newsletter

Pediatric Health-Care Professionals' Perceptions
and Practices of Family-Centred Care

Hi! My name is Nicole Letourneau and I am a student in the Masters of Nursing Program at the University of Alberta. I am studying **Pediatric Health-Care Professionals' Perceptions and Practices of Family-Centred Care**. This is part of a multi-site study about health-care professionals' across Canada. The research is also being done at the Izaak Walton Killam Hospital for Children in Halifax, Nova Scotia and the Children's Hospital of Western Ontario, in London, Ontario. The purpose of the study is to determine the perceptions and practices of health-care professionals caring for children and families in hospitals. I have been given permission to do this study from the Faculty of Nursing at the UNIVERSITY OF ALBERTA and Administration at the ALBERTA CHILDREN'S HOSPITAL.

Family-centred care is a relatively new concept for health-care professionals to put into practice. Your assistance in this study will contribute to a better understanding of current practice and may contribute to nationwide programming and policies that enhance the practice of family-centred care.

Health-care professionals from child life, medicine, nursing, nutritional therapy, occupational therapy, pharmacy, physiotherapy, psychology, respiratory therapy, social work, and speech/language pathology/audiology are being asked to participate in the study. The study involves completing a questionnaire taking about 20 minutes.

If you decide to participate, please return the questionnaire within **two weeks**, sealed in the envelope provided. Send them by internal mail to my sponsor **Laurie Wilson, Nursing Resources**. This is completely voluntary and returning the questionnaire serves as your consent. There will be no way of identifying whether or not any individual took part in the study as responses are totally anonymous. All questionnaire data gathered will be strictly confidential and no participant will be identifiable in any report of the study findings.

Nora Greenley, Vice President of Patient Care Services, may be contacted if you have any questions. Copies of the results will be available at the Alberta Children's Hospital and the Faculty of Nursing, University of Alberta. Thank you in advance for your interest and involvement in this study.

This research is funded in part by the National Health Research and Development Program and the Canadian Nurse's Foundation.

Yours sincerely,

Nicole Letourneau, BN, RN
Masters of Nursing Candidate
University of Alberta, Edmonton
Telephone: (403)433-3527

RESEARCH ON FAMILY-CENTRED CARE

You may be asked to participate in a study of pediatric health-care professionals' perceptions and practices of Family-Centred Care. Choosing to participate will enable you to express your views on this contemporary topic in children's health. For further information, contact Nicole Letourneau, RN, MN candidate at (403)433-3527 or Laurie Wilson, RN, BSN at local 7091. We will be happy to discuss the research and answer any of your questions.

Faculty of Nursing

University of Alberta

Edmonton, Alberta

Appendix H: Bulletin

Pediatric Health-Care Professionals' Perceptions
and Practices of Family-Centred Care

My name is Nicole Letourneau, RN, and I am a student in the Masters of Nursing Program at the University of Alberta. I am studying **Pediatric Health-Care Professionals' Perceptions and Practices of Family-Centred Care**. This is part of a multi-site study about health-care professionals' across Canada. The research is also being done at the Izaak Walton Killam Hospital for Children in Halifax, Nova Scotia and the Children's Hospital of Western Ontario, in London, Ontario. The purpose of the study is to determine the perceptions and practices of health-care professionals caring for families in the hospital setting.

Family-centred care is a relatively new concept for health-care professionals to put into practice. Your assistance in this study will contribute to a better understanding of current practice and may contribute to nationwide programming and policies that enhance the practice of family-centred care.

Health-care professionals from child life, medicine, nursing, nutritional therapy, occupational therapy, pharmacy, physiotherapy, psychology, respiratory therapy, social work, and speech/language pathology/audiology are being asked to participate in the study. The study involves completing a questionnaire taking about 20 minutes.

Should you decide to participate, please return the questionnaire within **two weeks**, sealed in the envelope provided. Send them by internal mail to my sponsor **Laurie Wilson, Nursing Resources**. This is completely voluntary and returning the questionnaire serves as your consent. There will be no way of identifying whether or not any individual took part in the study as responses are totally anonymous. All questionnaire data gathered will be strictly confidential and no participant will be identifiable in any report of the study findings.

Copies of the results will be available at the Alberta Children's Hospital and the Faculty of Nursing, University of Alberta. If you have any questions please contact me and I will reimburse your calling expenses. You may also contact Laurie Wilson at local 7091. Thank you for your interest and involvement in this study.

Yours sincerely,

Nicole Letourneau, RN, BN
Masters of Nursing Candidate
University of Alberta, Edmonton, Telephone: (403)433-3527

Appendix I: Cover Letter 1

Pediatric Health-Care Professionals' Perceptions and Practices of Family-Centred Care

Dear Alberta Children's Hospital Staff Member,

My name is Nicole Letourneau, RN, and I am a student in the Masters of Nursing Program at the University of Alberta. The topic of my Masters' Thesis is **Pediatric Health-Care Professionals' Perceptions and Practices of Family-Centred Care.** I am doing part of a multi-site study to determine the perceptions and practices of health-care professionals caring for families in various pediatric settings. I am working in collaboration with Beth Bruce, MN, Research Associate, Izaak Walton Killam Hospital for Children in Halifax, Nova Scotia and Christine Dennis, MN, Clinical Nurse Specialist, Children's Hospital of Western Ontario, in London, Ontario. I have been given permission by the Faculty of Nursing at the UNIVERSITY OF ALBERTA and ALBERTA CHILDREN'S HOSPITAL to do this study.

Health-care professionals from child life, medicine, nursing, nutritional therapy, occupational therapy, pharmacy, physiotherapy, psychology, respiratory therapy, social work, and speech and language pathology/audiology are asked to complete questionnaires. Filling out the survey will take about 20 minutes. Family-centred care is a relatively new concept for health-care professionals to put into practice. Your assistance in this study will contribute to a better understanding of current practice and may help develop programs and policies to assist with the delivery of family-centred care.

Should you decide to participate, please return the completed questionnaire within two weeks, sealed in the envelope addressed to Laurie Wilson, Nursing Resources. Participation in this study is completely voluntary and returning the survey serves as your consent. There will be no way of identifying whether or not you took part in the study as responses are totally anonymous. All questionnaire data will be strictly confidential and only grouped data will be reported in publications and presentations. The data gathered from this study will be analyzed in combination with the data from the other two sites. Completed questionnaires will be kept for a period of seven years and will be accessible to only myself and my thesis committee. Upon completion of the study, a copy of the results will be available at the Alberta Children's Hospital and the Faculty of Nursing, University of Alberta, Edmonton. If you have any questions regarding the study, I may be contacted at (403) 433-3527 or you may contact my thesis supervisor, Dr. M. Ruth Elliott, Professor at (403) 492-6241 and I will reimburse your calling expenses. Nora Greenley, Vice President of Patient Care Services, may also be contacted at local 7850 for further information. Thank you for your time and assistance. I look forward to sharing the results with you. Your participation is greatly appreciated.

Yours sincerely,

From:

To: Laurie Wilson, BSN, RN
Nursing Resources

Please send this postcard when you return your completed questionnaire **or** if you wish to be removed from the mailing list. When you return your completed questionnaire, ensure that you send the post card **separately**. This will remove you from the mailing list, save paper, and ensure the anonymity of your responses.

Appendix K: Cover Letter 2

Pediatric Health-Care Professionals' Perceptions and Practices of Family-Centred Care

Dear Alberta Children's Hospital Staff Member,

I would like to thank all of you who have volunteered time to fill out the questionnaire on family-centred care. This information will give a profile of some answers about the current state of family-centred care, and hopefully, will provide some information about health-care professionals' provision of family-centred care. Your response is extremely helpful and important.

If you have not had time to fill out the questionnaire, I urge you to do so in the coming week. It is important to hear from you in order to have reliable information on ways to enhance the practice of family-centred care. Again, I want to emphasize that all responses are totally anonymous and your confidentiality is guaranteed in the reporting of questionnaire data.

I have provided another questionnaire for your convenience. Please return your completed questionnaire in the outside reusable envelope. Simply stick the enclosed 'Laurie Wilson, Nursing Resources' return address label over your address.

If you have any questions please contact Nora Greenley, Vice President of Patient Care Services at local 7850. I may also be telephoned collect at (403) 433-3527. I greatly appreciate your time and participation in this study!

Yours sincerely,

Nicole Letourneau, RN, BN
Masters of Nursing Candidate
University of Alberta, Edmonton

Appendix L: Cover Letter 3

Pediatric Health-Care Professionals' Perceptions and Practices of Family-Centred Care

Dear Alberta Children's Hospital Staff Member,

This is a final reminder to those who have not yet had time to complete and return the previously mailed Family-Centred Care Questionnaire. The information you provide will help answer some of the questions about the current state of family-centred care, and hopefully, will enable the enhancement of family-centred care. Your response is extremely helpful and important.

If you have not had the time to fill out the questionnaire, I urge you to do so in the coming week. It is important to hear from you in order to have reliable information on which to base decisions to enhance the practice of family-centred care. Again, I want to emphasize that all responses are completely anonymous and your confidentiality is guaranteed.

Please return your completed questionnaire in the addressed envelope previously provided. If you have already done so, please accept my delighted thanks. Results of the study will be made available at the Alberta Children's Hospital and the University of Alberta Faculty of Nursing.

If you have any questions, do not hesitate to call me collect at (403) 433-3527. Nora Greenley may also be contacted at local 7850 for more information. I greatly appreciate your time and participation in this study!

Yours sincerely,

Nicole Letourneau, RN, BN
Masters of Nursing Candidate
University of Alberta, Edmonton

FAMILY-CENTRED CARE QUESTIONNAIRE REVISED
© Copyright by Beth S. Bruce 1993

The following questions refer to your beliefs about what family-centred care is or is not. We are interested in knowing how well these items represent your practice and beliefs of family-centred care.

DIRECTIONS:

CURRENT

Carefully think about each item with respect to the extent to which you include this aspect of care in your everyday work. Mark the appropriate letters that indicate your response under the current column.

NECESSARY

Carefully think about each item with respect to whether you believe that this aspect of care is necessary for family-centred care to be provided. Mark the appropriate letters that indicate your response under the necessary column.

EXAMPLE:

STRONGLY AGREE SA | AGREE A | NEUTRAL N | DISAGREE D | STRONGLY DISAGREE SD

	Current					Necessary				
Staff encourage families to attend patient care conferences.	SA	A	N	D	SD	SA	A	N	D	SD

DEFINITIONS:

For the purposes of this study, Staff refers to the health care professionals who are being surveyed in this study; nurses, physicians, child life specialists, social workers, psychologists, nutritionists, physiotherapists, occupational therapists and respiratory therapists. Family refers to parents, guardians, grandparents, and siblings, and any family friend who is significantly involved with the child's everyday life or care.

FAMILY-CENTRED CARE QUESTIONNAIRE-REVISED

STRONGLY AGREE SA AGREE A NEUTRAL N DISAGREE D STRONGLY DISAGREE SD

	Current					Necessary				
1. Staff encourage parents and siblings to come and go any time that meets the family's needs.	SA	A	N	D	SD	SA	A	N	D	SD
2. Staff work with families to determine the level of participation in direct care and decision-making that suits the family's needs best.	SA	A	N	D	SD	SA	A	N	D	SD
3. The family is the key decision maker in the care of their child.	SA	A	N	D	SD	SA	A	N	D	SD
4. Staff determine the child's needs in consultation with the family and other health professionals.	SA	A	N	D	SD	SA	A	N	D	SD
5. Parents contribute to the development and review of hospital policies and practices.	SA	A	N	D	SD	SA	A	N	D	SD
6. Parents and siblings are involved in staff orientation and continuing education programs.	SA	A	N	D	SD	SA	A	N	D	SD
7. Educational programs and written material convey the sense that families are the key participants in care.	SA	A	N	D	SD	SA	A	N	D	SD
8. The admission process is used as an opportunity to begin involving the family as members in the health care team.	SA	A	N	D	SD	SA	A	N	D	SD
9. Hospital facilities, policies, and procedures foster family choices for participation.	SA	A	N	D	SD	SA	A	N	D	SD
10. Interviews with families are conducted in a private location.	SA	A	N	D	SD	SA	A	N	D	SD
11. Explanations are presented to the family,using a variety of techniques depending on the individual needs and learning styles of the family.	SA	A	N	D	SD	SA	A	N	D	SD
12. Staff are aware of and take approaches that address the fact that families take time to develop trust.	SA	A	N	D	SD	SA	A	N	D	SD
13. Staff discuss with the child and family what helps them deal with events during hospitalization.	SA	A	N	D	SD	SA	A	N	D	SD
14. Staff assess the level of understanding and skills of the child and family before and after teaching.	SA	A	N	D	SD	SA	A	N	D	SD
15. Staff promote preadmission programs which familiarize children and families with hospital staff, routines, and equipment prior to a scheduled admission.	SA	A	N	D	SD	SA	A	N	D	SD

STRONGLY AGREE SA AGREE A NEUTRAL N DISAGREE D STRONGLY DISAGREE SD

	Current					Necessary				
16. After an emergency admission or unscheduled admission, there is an organized system for helping children and families understand and adjust to the health care experience.	SA	A	N	D	SD	SA	A	N	D	SD
17. Information is routinely communicated to help families understand each aspect of care that their child will experience such as anticipated sequence of events, reasons for change/treatment/procedure, ways to cope.	SA	A	N	D	SD	SA	A	N	D	SD
18. Any family member significantly involved in the child's care is encouraged to discuss or chart information about the care of their child.	SA	A	N	D	SD	SA	A	N	D	SD
19. Staff coordinate the flow and sequence of information given to children and their families, ensuring that the child's information needs are a priority.	SA	A	N	D	SD	SA	A	N	D	SD
20. Staff encourage parents to discuss concerns with other parents with other parents with similar experiences informally or in formal parent groups.	SA	A	N	D	SD	SA	A	N	D	SD
21. Staff provide programs and support for parents, siblings and members of the extended family to assist families in managing needs.	SA	A	N	D	SD	SA	A	N	D	SD
22. Staff assess the needs and concerns of siblings.	SA	A	N	D	SD	SA	A	N	D	SD
23. There is a designated comfortable area for parents to gather.	SA	A	N	D	SD	SA	A	N	D	SD
24. Staff help children and family stay in touch with their family and friends.	SA	A	N	D	SD	SA	A	N	D	SD
25. Direct care managers have an adequate knowledge in child development to support hospital staff in the practice of family-centred care.	SA	A	N	D	SD	SA	A	N	D	SD
26. Hospital brochures accurately describe the health care experience for children and their families.	SA	A	N	D	SD	SA	A	N	D	SD
27. Staff maintain familiar routines for each child and family.	SA	A	N	D	SD	SA	A	N	D	SD
28. Staff assess the child's interaction with staff, peers and family.	SA	A	N	D	SD	SA	A	N	D	SD
29. When possible, the same staff are assigned to care for the child and family.	SA	A	N	D	SD	SA	A	N	D	SD
30. Information and support are provided to help families understand the illness process and the impact on the child and family, choices and risks, services, and roles of various health professionals.	SA	A	N	D	SD	SA	A	N	D	SD
31. Staff recognize the financial strain on families and assist them in obtaining help.	SA	A	N	D	SD	SA	A	N	D	SD

STRONGLY AGREE SA | AGREE A | NEUTRAL N | DISAGREE D | STRONGLY DISAGREE SD

	Current					Necessary				
32. During procedures, a staff member is designated to explain to the child and family exactly what is happening.	SA	A	N	D	SD	SA	A	N	D	SD
33. Nonurgent outpatient services are available daily and in the evening hours.	SA	A	N	D	SD	SA	A	N	D	SD
34. All written material for families is available in French/English versions.	SA	A	N	D	SD	SA	A	N	D	SD
35. A written summary of relevant information about the child is available in the primary official language of the family.	SA	A	N	D	SD	SA	A	N	D	SD
36. The physical layout of the unit is designed to meet the developmental and psychosocial needs of the child and family.	SA	A	N	D	SD	SA	A	N	D	SD
37. Resources exist to help provide families with the appropriate support that they need at varying times.	SA	A	N	D	SD	SA	A	N	D	SD
38. Parent evaluations are considered reliable sources of information about how well the hospital meets their needs.	SA	A	N	D	SD	SA	A	N	D	SD
39. Staffing patterns are planned according to the developmental and psychosocial needs of children.	SA	A	N	D	SD	SA	A	N	D	SD
40. There are guidelines to assist staff in providing care during painful procedures such as: teaching children ways to cope with pain and post-procedural debriefing of the child.	SA	A	N	D	SD	SA	A	N	D	SD
41. Job descriptions and performance appraisal systems incorporate expectations of family-centred care such as: knowledge of family dynamics and skills in collaboration, problem solving and interventions that address family's needs.	SA	A	N	D	SD	SA	A	N	D	SD
42. Continuing education programs provide opportunities for staff to learn to deal effectively with families.	SA	A	N	D	SD	SA	A	N	D	SD
43. The hospital recognizes and rewards special knowledge and skills that are needed to care for children and families.	SA	A	N	D	SD	SA	A	N	D	SD
44. Staff are encouraged to identify, plan and evaluate new programs, policies and procedures to improve the quality of patient and family care.	SA	A	N	D	SD	SA	A	N	D	SD
45. Staff are able to express confidentially to those responsible for assuring quality care, their concerns related to those demands of providing care for their children and families.	SA	A	N	D	SD	SA	A	N	D	SD

PLEASE WRITE ANY ADDITIONAL COMMENTS BELOW

SUGGESTIONS OF WHAT IS NEEDED TO ENHANCE FAMILY-CENTRED CARE

DEMOGRAPHIC SHEET

Please complete the following general information.

1. AGE (years)
   - 20-30 _____
   - 31-40 _____
   - 41-50 _____
   - 51-60 _____
   - over 60 _____

2. YEARS OF EXPERIENCE AT THIS INSTITUTION _____

3. CLINICAL POSITION
   - Administrative Position _____
   - Manager _____
   - Education _____
   - Staff _____

4. HIGHEST LEVEL OF EDUCATION
   - University degree _____
   - Post Secondary _____
   - Other _____

5. HEALTH PROFESSION
   - Nurse _____
   - Physician _____
   - Child Life Specialist _____
   - Social Worker _____
   - Psychologist _____
   - Physiotherapist _____
   - Occupational Therapist _____
   - Respiratory Therapist _____
   - Nutritionist _____

Appendix N

Original File: Factor Loadings and Eigenvalues for Perceptions Scale

	FR1	FR2	FR3	FR4	FR5	FR6	FR7	FR8	FR9
V1								.75	
V2							.45		
V3									-.7
V4							-.7		
V5						.68			
V6						.81			
V7					.35	.46			
V8		.35						.39	
V9									
V10	.63								
V11	.71								
V12	.61								
V13	.44								
V14	.74								
V15									
V16		.41							
V17	.66								
V18			.45		.42				
V19	.43								
V20					.47				
V21	.36		.54						
V22			.59						
V23			.67						
V24			.64						
V25		.39							
V26			.51						

V27			.55				.37		
V28		.45					.41		
V29	.44								.44
V30	.40	.59							
V31	.40	.42							
V32		.56							
V33					.66				
V34			.36		.62				
V35					.60				
V36		.61							
V37		.62							
V38		.57							
V39		.40		.53					
V40		.39	.40						
V41		.38		.49					
V42		.35		.45					
V43				.71					
V44				.64					
V45				.62					
EIG	13.5	2.14	1.71	1.70	1.50	1.46	1.45	1.31	1.2
PCT VAR	29.9	4.8	3.8	3.8	3.3	3.2	3.2	2.9	2.6
CUM PCT	29.9	34.7	38.5	42.2	45.6	48.8	52.0	54.9	58

V=Variable
FR=Factor
EIG=Eigenvalue
PCT VAR=Percent of Variance
CUM PCT=Cumulative Percent

Appendix O

Original File: Factor Loadings and Eigenvalues for Practice Scale

	FR1	FR2	FR3	FR4	FR5	FR6	FR7	FR8	FR9
V1								.69	
V2					.65				
V3					.62				
V4					-.6				
V5							.65		
V6									
V7							.84		
V8					.40				
V9						.59			
V10									
V11	.58				.36				
V12	.68								
V13	.48				.36				
V14	.64								
V15								.56	
V16		.46		.44					
V17	.52								
V18	.59								
V19	.62								
V20	.37								
V21		.49							
V22		.69							
V23		.35				.36			
V24		.71							
V25			.51						
V26						.75			

V27	.65								
V28	.41	.44							
V29									.69
V30		.41							
V31	.47								
V32	.53								
V33				.51					
V34				.69					
V35			.38	.58					
V36						.44			
V37		.60							
V38	.39								
V39									
V40				.38					-.4
V41			.45					.50	
V42			.51						
V43			.71						
V44			.39						
V45			.55						
EIG	10.8	2.67	1.89	1.71	1.56	1.41	1.36	1.34	1.3
PCT VAR	24.1	5.9	4.2	3.8	3.5	3.1	3.0	3.0	2.8
CUM VAR	24.1	30.0	34.2	38.0	41.5	44.6	47.6	50.6	53

V=Variable
FR=Factor
EIG=Eigenvalue
PCT VAR=Percent of Variance
CUM PCT=Cumulative Percent

Appendix P

Final File: Factor Loadings and Eigenvalues for Perceptions Scale

	FR1	FR2	FR3	FR4	FR5	FR6	FR7	FR8	FR9
V1									
V2	.40					.52			.70
V3							.67		
V4						-.7			
V5					.36		.59		
V6							.66		
V7							.58		
V8	.37								
V9			.36						
V10	.43								-.4
V11	.72								
V12	.65								
V13	.54								
V14	.68								
V15			.52						
V16			.57						
V17	.70								
V18		.41							
V19			.35	.39					
V20							.37	.40	
V21			.57	.43					
V22		.63							
V23		.67							
V24		.55							
V25									
V26		.39	.44						

V27		.38	.36			.40			
V28						.54			
V29			.62						
V30	.36		.40						
V31		.38							
V32						.49			
V33								.64	
V34			.36					.57	
V35								.69	
V36		.42			.44				
V37		.63							
V38		.57				.36			
V39						.40			
V40					.62				
V41					.65				
V42					.49				
V43				.69					
V44				.60					
V45				.66					
EIG	13.2	1.99	1.87	1.69	1.65	1.54	1.34	1.23	1.2
PCT VAR	29.3	4.4	4.1	3.8	3.7	3.4	3.0	2.7	2.6
CUM PCT	29.3	33.7	37.9	41.6	45.3	48.7	51.7	54.4	57

V=Variable
FR=Factor
EIG=Eigenvalue
PCT VAR=Percent of Variance
CUM PCT=Cumulative Percent

Appendix Q

Final File: Factor Loadings and Eigenvalues for Practice Scale

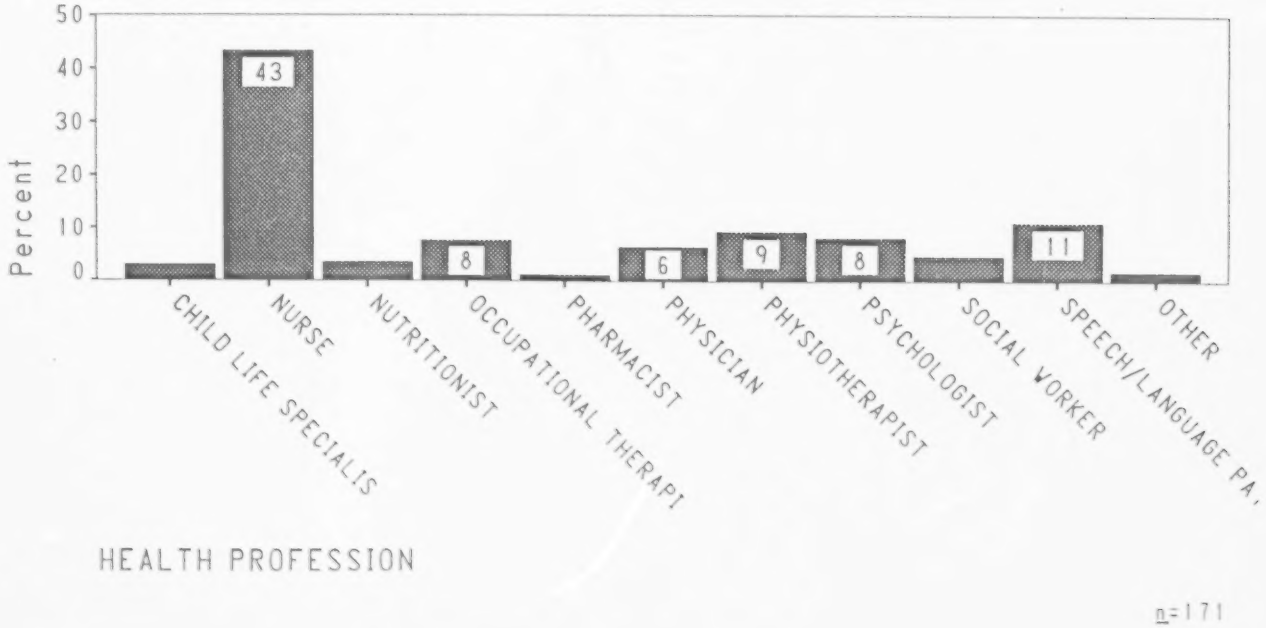
	FR1	FR2	FR3	FR4	FR5	FR6	FR7	FR8	FR9
V1							.63		
V2			.69						
V3			.66						
V4			-.54						
V5								.57	
V6								.83	
V7									.38
V8									
V9						.60			
V10				.35					
V11	.55		.36						
V12	.69								
V13	.49								
V14	.65								
V15							.61		
V16		.49		.39					
V17	.56								
V18	.54								
V19	.64								
V20			.39						
V21		.41							
V22		.67							
V23			.36			.41			
V24		.60							
V25		.39			.45				
V26						.79			

V27	.63								
V28	.38	.54							
V29									.60
V30		.53							
V31	.45								
V32	.55								
V33				.57					
V34				.70					
V35				.62					
V36						.50			
V37		.64							
V38	.46								
V39									
V40				.40					-.5
V41							.61		
V42					.50				
V43					.72				
V44		.44	.35						
V45		.39			.56				
EIG	10.6	2.64	1.99	1.79	1.61	1.49	1.46	1.38	1.3
PCT VAR	23.6	5.9	4.4	4.0	3.6	3.3	3.2	3.1	3.0
CUM VAR	23.6	29.5	33.9	37.9	41.5	44.8	48.0	51.1	54

V=Variable
FR=Factor
EIG=Eigenvalue
PCT VAR=Percent of Variance
CUM PCT=Cumulative Percent

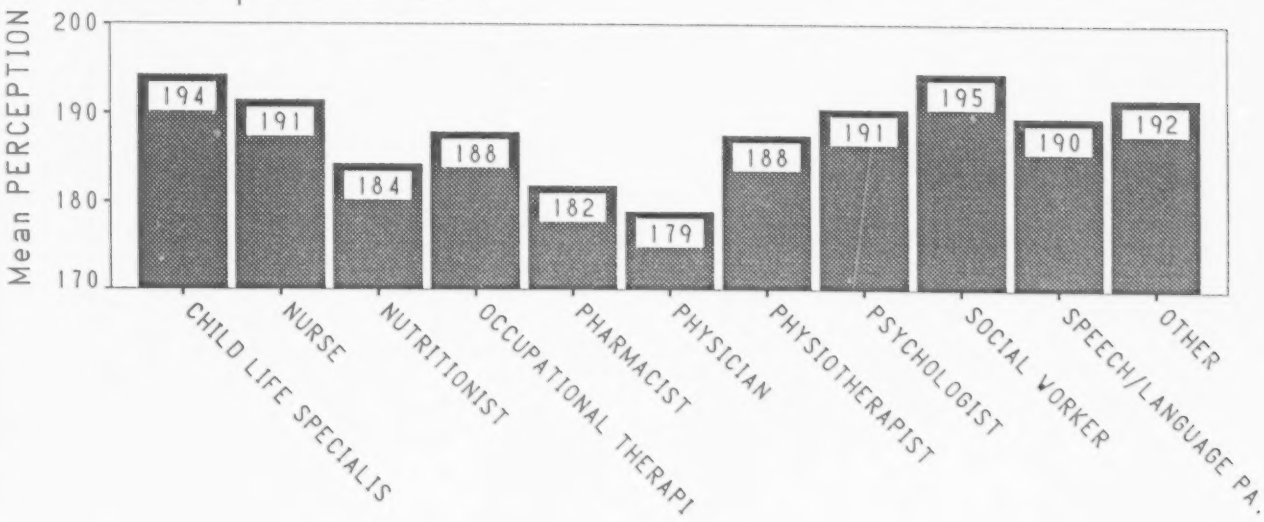
Appendix R: Figures

Figure 1. Sample percentages by health-care profession.



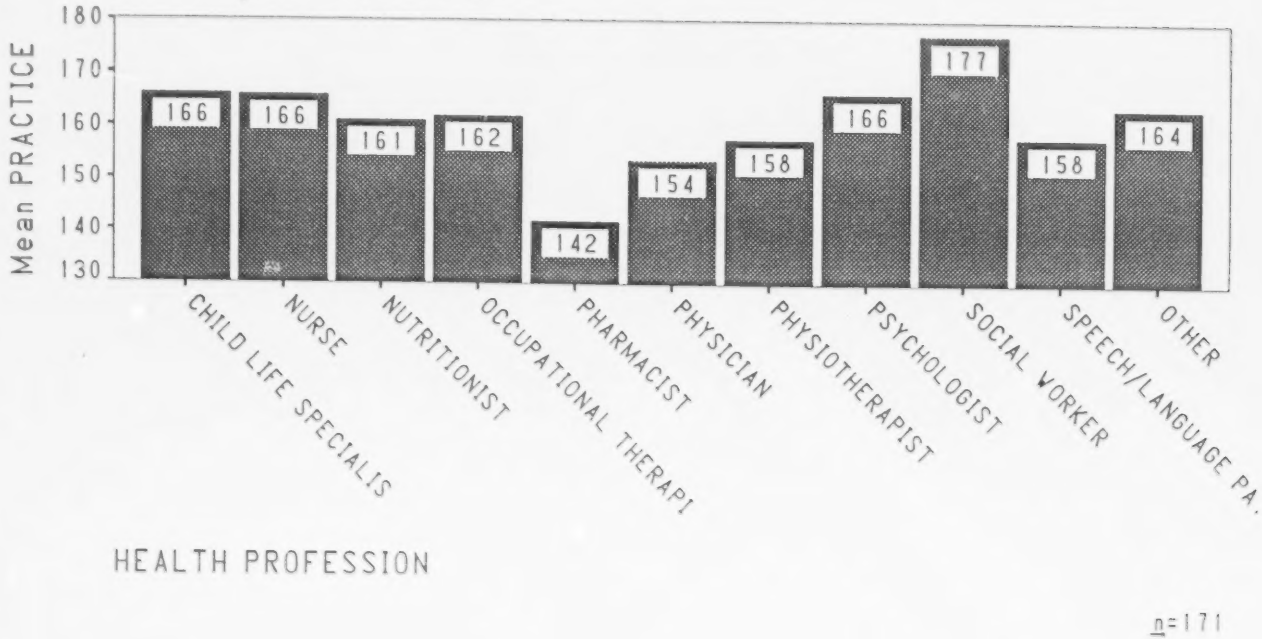
n=171

Figure 2. Mean perception scores by health-care profession.



n=171

Figure 3. Mean practice scores by health-care profession.



n=171

Figure 4A. Sample subgroup counts by area of employment.

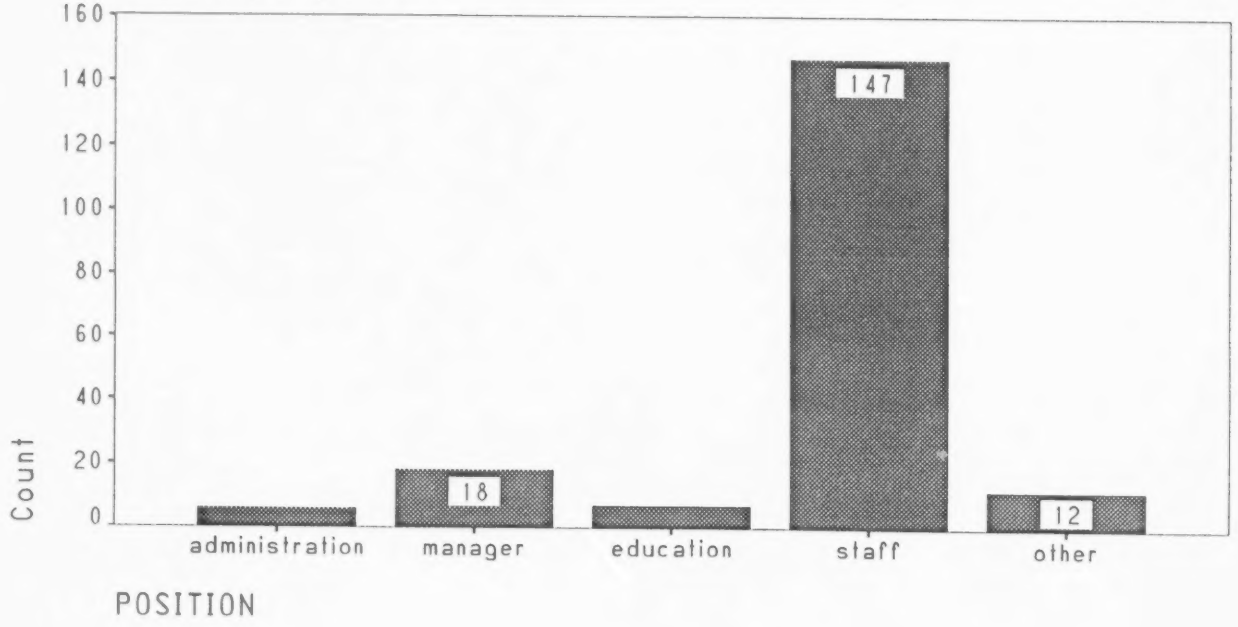
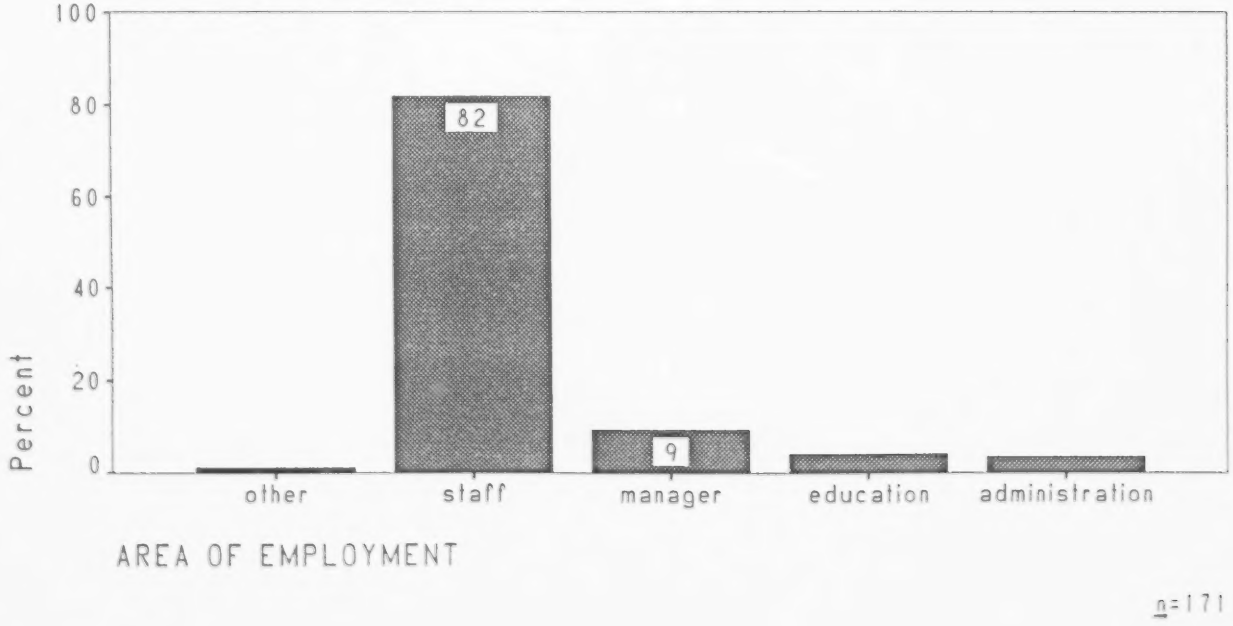
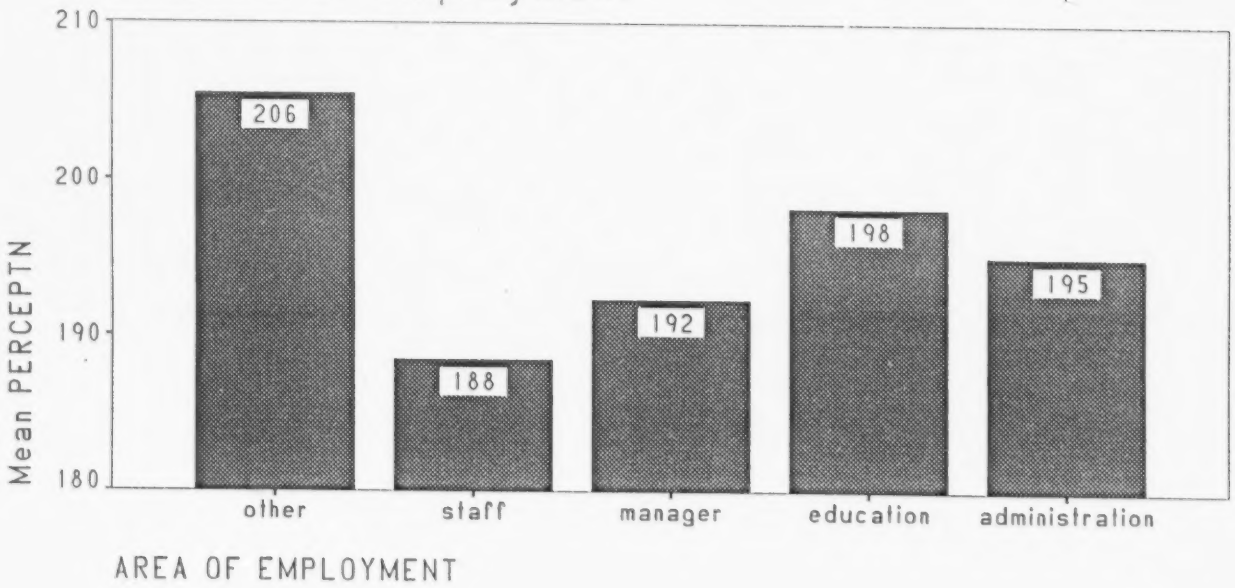


Figure 4B. Sample percentages for recoded area of employment.



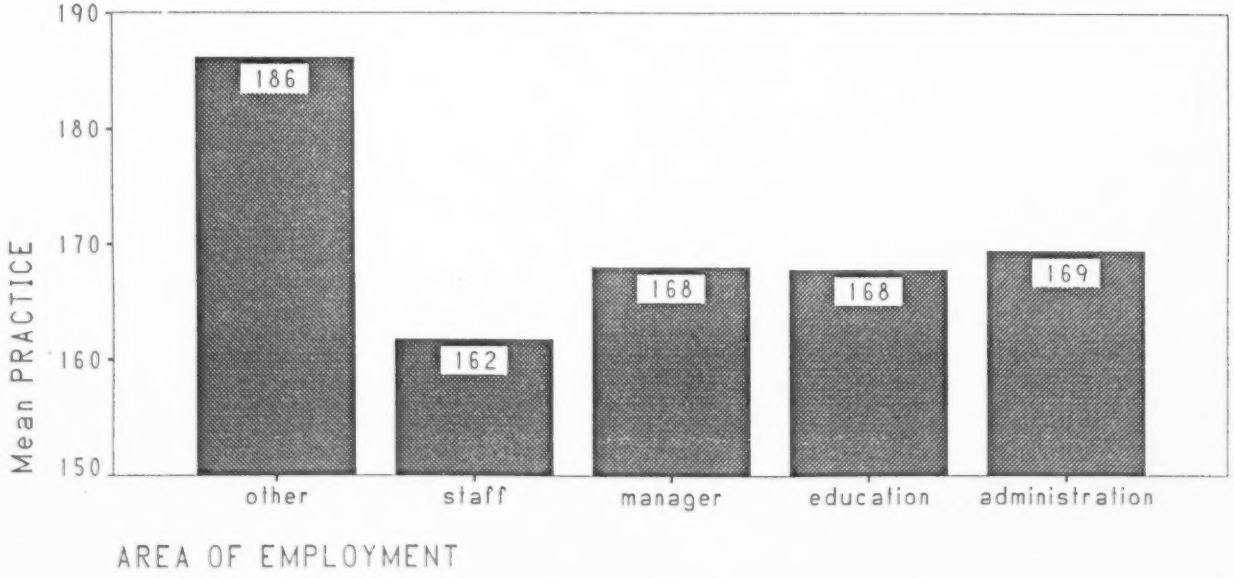
n=171

Figure 5. Mean perception scores by recode of area of employment



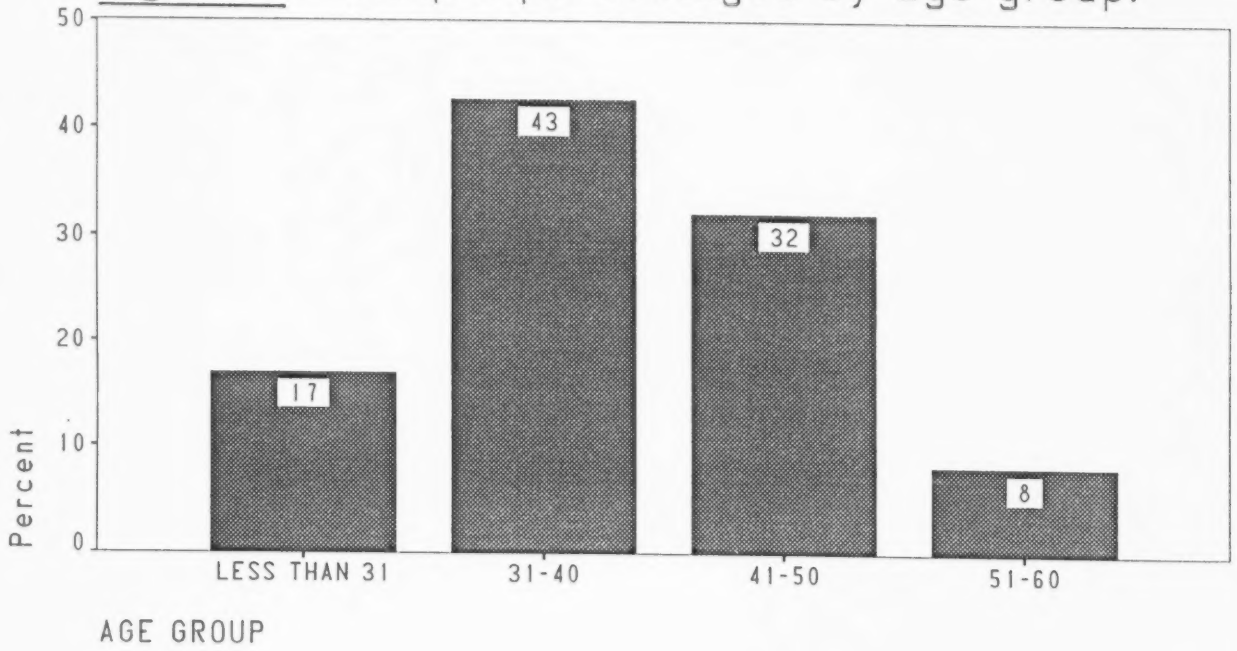
n=171

Figure 6. Mean practice scores by recode of area of employment



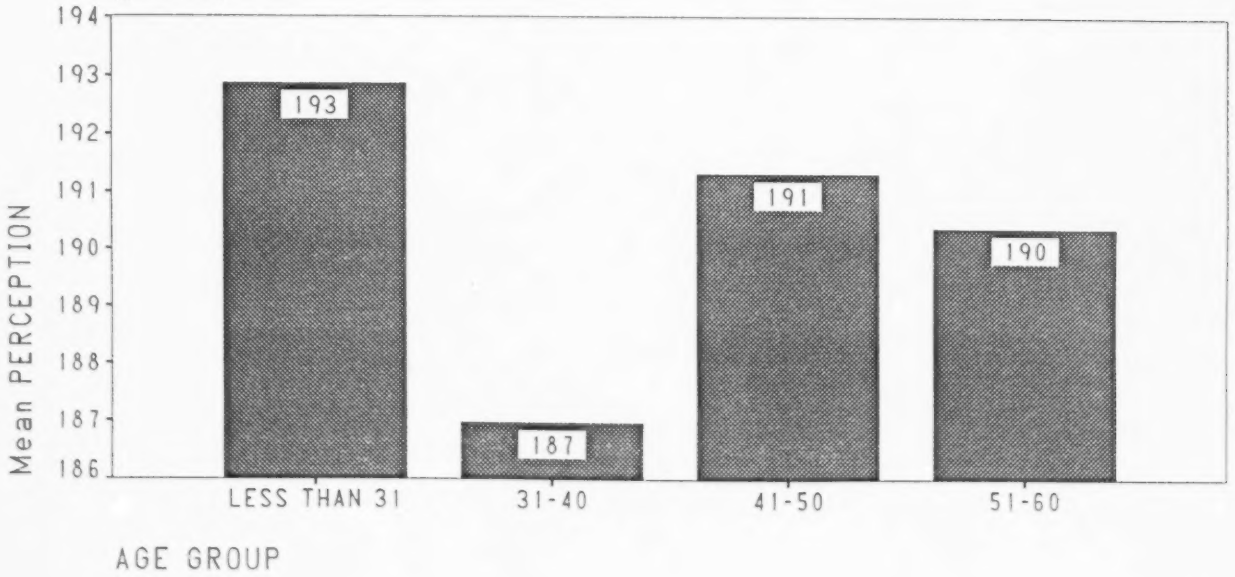
n=171

Figure 7. Sample percentages by age group.



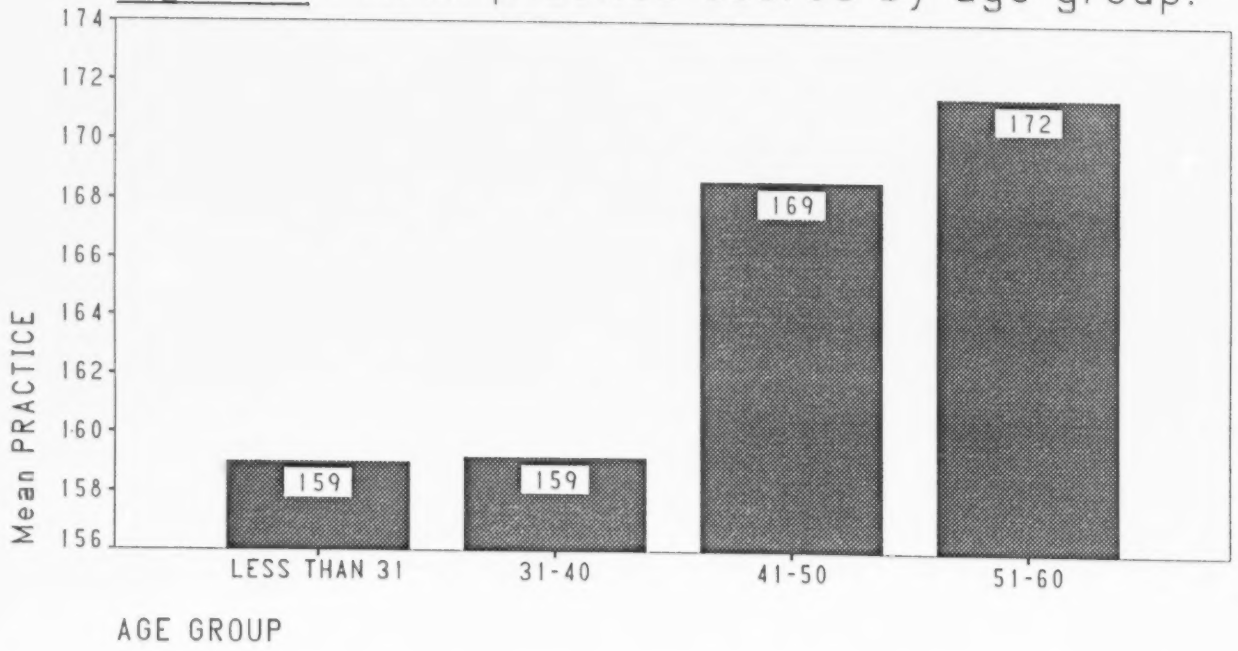
n=171

Figure 8. Mean perception scores by age group.



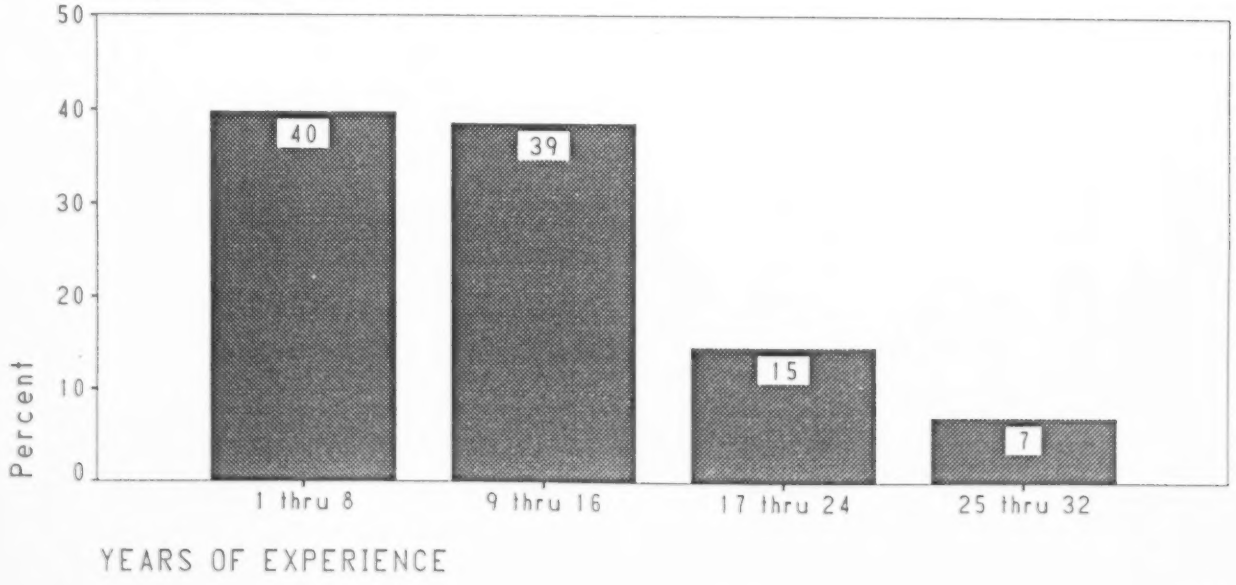
n=171

Figure 9. Mean practice scores by age group.



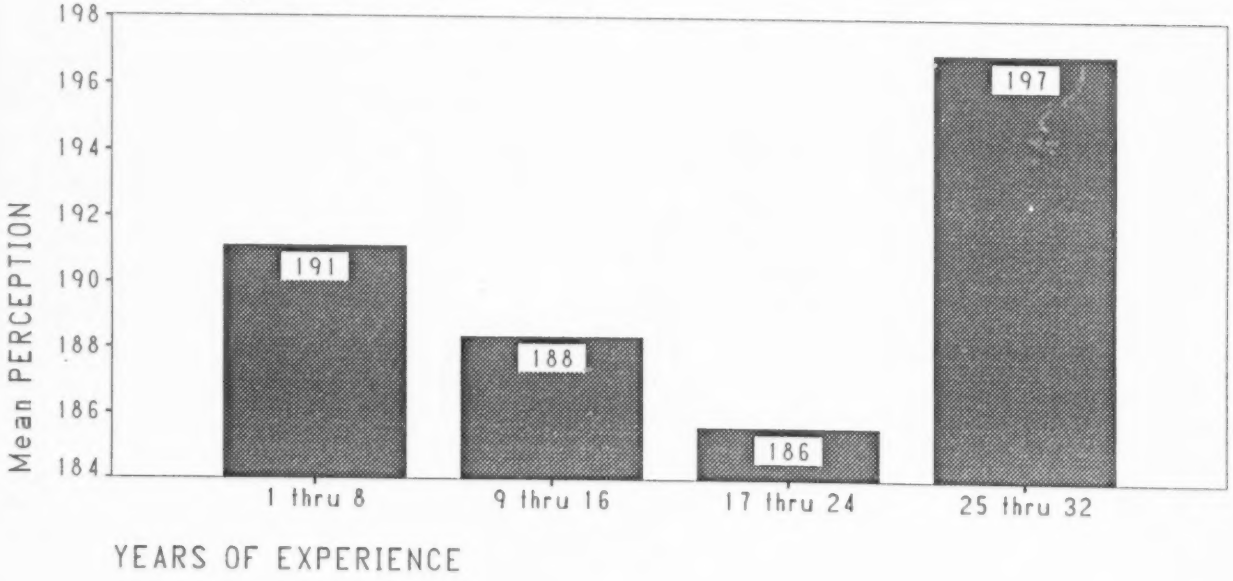
n=171

Figure 10. Sample percentages by years of experience.



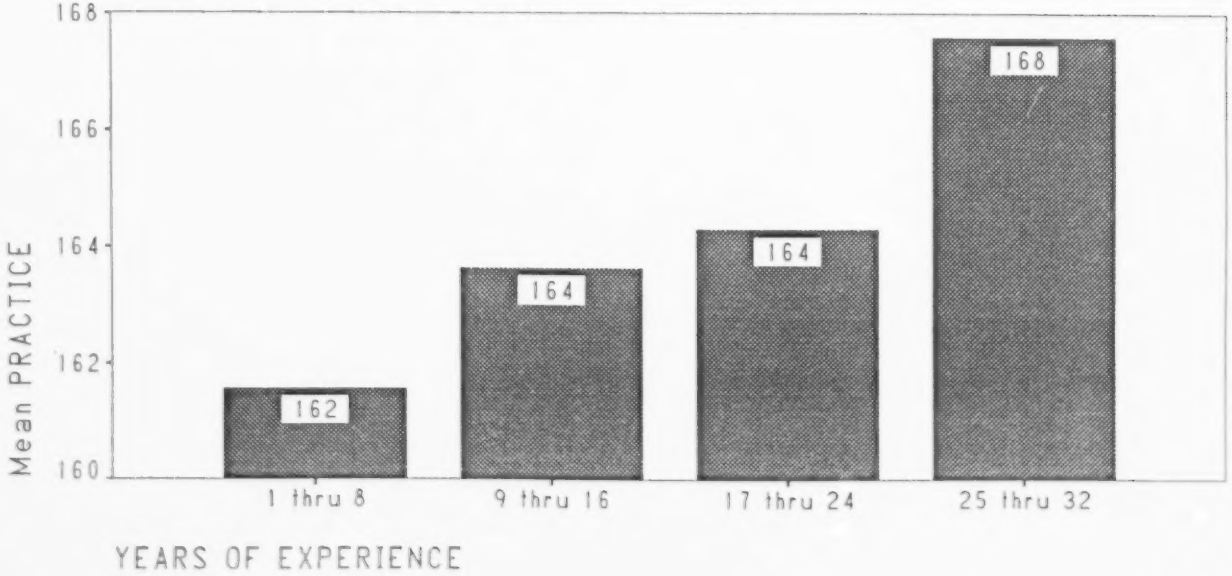
n=171

Figure 11. Mean perception scores by years of experience.



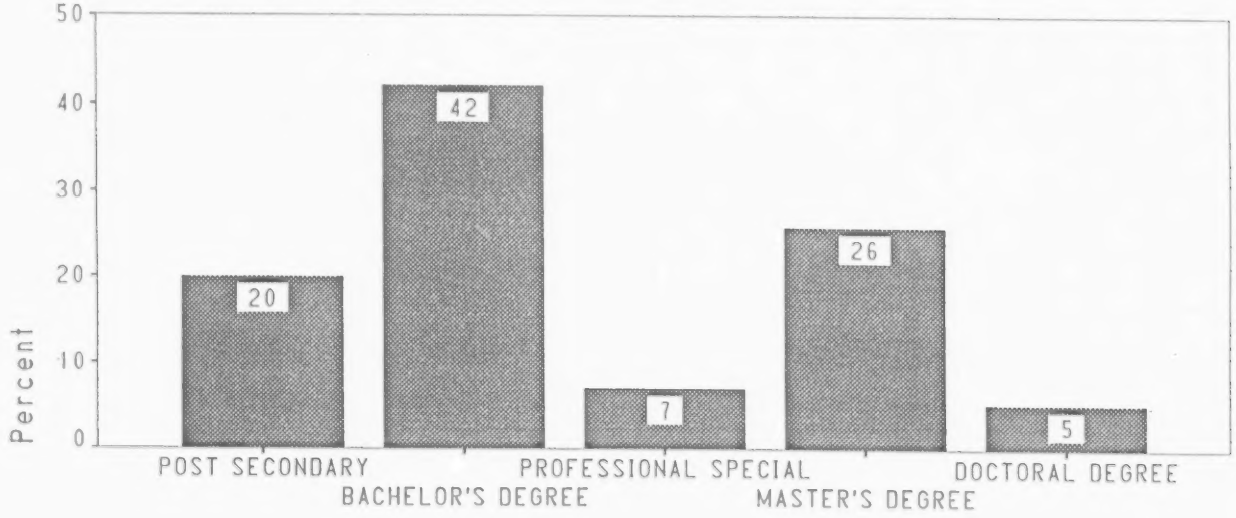
n=171

Figure 12. Mean practice scores by years of experience



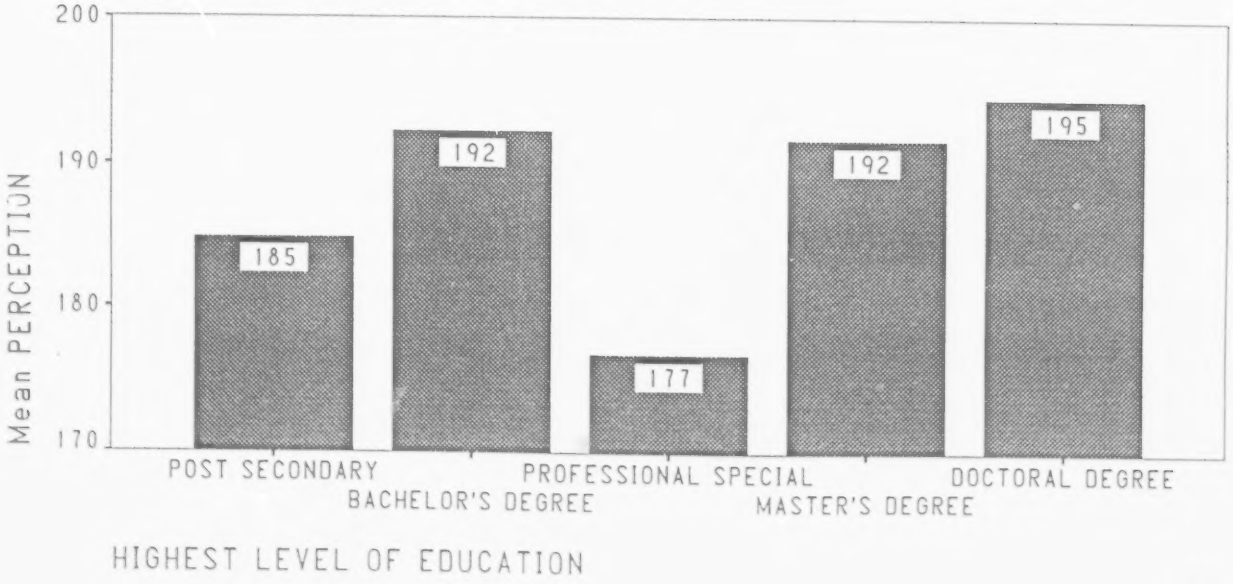
n=171

Figure 13. Sample percentages by highest level of education.



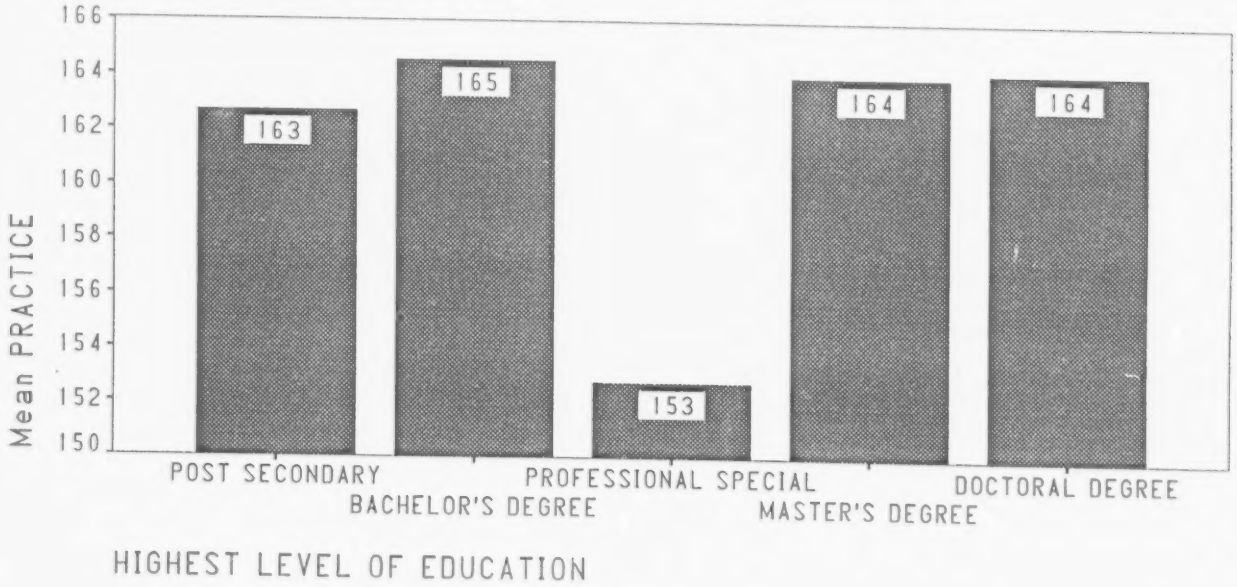
n=171

Figure 14. Mean perception scores by highest level of education.



n=171

Figure 15. Mean practice scores by highest level of education.



n=171

Appendix S

FCCQ-R Item Mean Scores From Lowest to Highest

n=necessary, ew=everyday work

ITEM	MEAN	SD	RANGE	MIN	MAX	VALID N
var04n	1.52	.87	4	1	5	170
var04ew	1.62	.87	4	1	5	170
var34ew	2.06	.97	4	1	5	154
var06ew	2.44	1.15	4	1	5	158
var35ew	2.45	1.23	4	1	5	163
var43ew	2.75	1.25	4	1	5	166
var33ew	2.93	1.29	4	1	5	150
var05ew	2.97	1.04	4	1	5	166
var39ew	3.05	1.34	4	1	5	163
var34n	3.09	1.11	4	1	5	163
var16ew	3.15	1.09	4	1	5	135
var06n	3.21	1.06	4	1	5	166
var41ew	3.30	1.23	4	1	5	164
var22ew	3.32	1.6	4	1	5	164
var24ew	3.50	1.04	4	1	5	144
var23ew	3.50	1.16	4	1	5	163
var09ew	3.54	0.95	4	1	5	181
var18ew	3.60	1.09	4	1	5	163
var45ew	3.61	1.09	4	1	5	171
var26ew	3.62	0.93	4	1	5	164
var40ew	3.64	1.04	4	1	5	132
var44ew	3.67	1.04	4	1	5	169
var05n	3.67	0.94	4	1	5	171
var36ew	3.69	1.14	4	1	5	162
var21ew	3.72	1.04	4	1	5	166
var01ew	3.75	1.12	4	1	5	15

var19ew	3.76	0.90	4	1	5	169
var07ew	3.76	0.99	4	1	5	171
var27ew	3.76	0.83	3	2	5	167
var35n	3.77	0.93	4	1	5	168
var33n	3.80	0.98	4	1	5	163
var42ew	3.82	0.98	4	1	5	170
var01n	3.86	1.09	4	1	5	160
var37ew	3.88	0.99	4	1	5	171
var24n	3.90	0.84	4	1	5	162
var25ew	3.95	1.01	4	1	5	165
var20ew	3.95	0.82	4	1	5	169
var03ew	3.96	1.00	4	1	5	171
var10ew	3.98	1.01	4	1	5	170
var18n	4.00	0.87	4	1	5	167
var08ew	4.02	0.96	4	1	5	164
var17ew	4.04	0.94	4	1	5	171
var15ew	4.04	0.94	4	1	5	137
var38ew	4.05	0.78	3	2	5	169
var14ew	4.08	0.86	3	2	5	169
var32ew	4.11	0.95	4	1	5	161
var22n	4.11	0.75	4	1	5	166
var31ew	4.16	0.75	3	2	5	169
var39n	4.17	0.83	4	1	5	168
var13ew	4.17	0.81	4	1	5	149
var29ew	4.18	0.82	4	1	5	168
var30ew	4.19	0.76	4	1	5	170
var27n	4.20	0.69	3	2	5	166
var28ew	4.21	0.72	4	1	5	168
var11ew	4.22	0.82	4	1	5	171
var43n	4.22	0.71	4	1	5	168
var41n	4.23	0.66	4	1	5	169
var03n	4.24	0.85	4	1	5	180